Trapped: An examination of the ethics of incapacitated patient care And clinical research

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An abstract of
A thesis submitted to the Faculty of the
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Abstract

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Trapped dramatizes and dissects ethical dilemmas involved in caring for terminally ill, incapacitated patients who cannot make decisions about their treatment, do not have advance directives, and do not have surrogate decision makers. Patients are often diagnosed by the attending medical professionals as comatose or in a persistent vegetative state with no hope of regaining consciousness. Further aggressive treatment is considered futile and withholding or withdrawing life sustaining care is recommended. *Trapped* depicts a patient with locked-in syndrome misdiagnosed as comatose. He is completely paralyzed and unable to communicate, but is conscious and narrates the events surrounding his care as the medical professionals in a neurological intensive care unit move toward withdrawal of life support. A technical description of locked-in syndrome and an ethical analysis of key issues raised follow the story. The first issue is the process by which decisions are made to withhold and withdraw life sustaining treatment from incapacitated patients without surrogate decision makers or advance directives. A recommendation is made to augment current standard procedure. Also analyzed are the practice of issuing do-not-resuscitate (DNR) orders for these patients and whether to enroll incapacitated patients in clinical research. Finally, specific recommendations are proposed for standardized, systematic policies for decision making.

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Chapter

Awakening

It's morning; that much I know. The light is soft and has gradually brightened wherever it is I am. I'm lying down, staring at a white ceiling. I feel strange, hazy, as if I'm tucked inside a dense cloud. I hear, but can't make out the sounds; maybe if I stand up, get my feet on the ground, I'll get my bearings. I hope I don't fall. What's wrong? I can't swing my legs around or push up with my hands. I can't move my head. I'll call for help. What if no one is here? What's happened to my voice? My mouth won't move. Who's there? A big woman, wearing a blue smock leans in close to my face and peers intently into my eyes like she's searching for something. "Hey," she whispers with the scent of coffee breath, "you are one weird looking dude." She shudders and pulls back.

My cloud is beginning to dissolve a bit. I hear a man say, "It's Friday, July 6, News at 9 next." Now more sounds, chirps and beeps. What are they? And there are distant muted voices. Air is rushing down my windpipe and into my lungs. They expand and contract. I'm breathing, but it's not me. I'm urinating. Where's it going? Don't pass out. Get up. I'm so tired, exhausted. I don't think I could take one step. I have to try. But nothing happens. Who's that? An older man, I think, with a gravelly, impatient voice.

"What do we have here?"

I wish I could see what's happening. There's a lot of commotion, people mumbling. Now several are staring down at me. Some are wearing white coats and others blue smocks. Their faces are surreal, blank, as if they don't know I see them. Help, I scream, where am I?

Another man, younger, with smooth, unhurried, speech: "He's a 77-year-old white male. He suffered a basilar artery ischemic stroke resulting in brain stem damage.

Here’s the CT scan we did the day after he arrived here. You can see indications of the damage. It’s difficult to tell the extent. There’s also no indication of neuronal activity in the upper portions of his brain. He’s completely paralyzed, unresponsive and comatose. There is no eye movement of any kind. Not even blinking.”

“How long has he been like this?” the older man asks.

“He’s been here eight days with no change,” the younger one says.

“What about an EEG?” the older one continues.

“It also shows damage to the brain stem and no significant activity to indicate awareness. We’ve also conducted the standard behavioral tests several times and there’s absolutely no response.”

“What about the clot?” the questioner continues.

“The ER surgeons didn’t remove it. They figured he was about dead. They just shipped him to the ICU so he wouldn’t die in the emergency room. Obviously, their prognosis was wrong. He didn’t arrive at the ER in time to administer tPA. The window of opportunity is only about four hours from onset of stroke. He was walking through a park and collapsed. Apparently there was no one around. The EMTs did not know how long he was down, and they were slow getting him to the ER. Given how he looked, they thought he was dead when they first saw him.”

“What about co-morbidities?”

“His blood pressure was through the roof. It’s likely a chronic condition that wasn’t being treated. He’s stable,” the younger man observes. “But he also has elevated levels of protein in his urine, suggesting kidney problems. He doesn’t need dialysis at this point. Blood glucose is normal.”

“How long do we expect this gentleman to be a guest in our ICU? Have you tried to see if he can breathe on his own? Why is he trached? It’s more expensive than an endotracheal tube.”

“That was how he arrived here, Dr. Sherman,” the younger man says. “Given the distortion of his face and jaw, inserting an endotracheal tube would have been difficult. He was trached in the ER. At this point we still don’t have a firm diagnosis. I was waiting to see if he improved before we risk trying to find out if he can breathe on his own.”

“It’s been eight days already and no change? Dr. Peabody you saw the same memo from the hospital CEO that I did,” Sherman says. “This hospital lost $200 million last year. You said he was about dead when he arrived. It’s time we did something with this patient.

“I don’t see anything in the EEG or the CT scan that indicates he’s going to recover consciousness,” Sherman says. “When did you say the tests were conducted?”

“We did the CT scan two days after he arrived and the EEG three days ago. It’s been busy around here the past two days,” Peabody says. “This is the first time we’ve had a chance to review the CT scan and EEG together.”

“All right, that makes sense. Do we know who he is? Does he have any relatives? Who’s the decision maker? Is he at least a paying customer? Does he have a DNR? And can we please close his eyes? He looks bizarre. In all my years here I’ve never seen anything like it.”

“Dr. Sherman, if you mean we should close his eyelids to keep his eyes from drying out and to keep him from getting an infection, we have been covering his eyes and giving him lubricants and ointment regularly for the past several days,” Peabody says. “I don’t think you want his medical chart to reflect ‘looking bizarre’ as a reason for shutting his eyelids. One of the residents suggested sewing them shut, but I don’t think we should take that step yet.”

“Come on, Dr. Peabody, get on with it.”

“The patient’s name is Wilbur Force. He lives alone in a condo in a retirement community. As far as family, the social worker found a brother, but he doesn’t want to make decisions or have anything to do with him. The brother hasn’t talked to him for decades; some sort of falling out over their parents. There apparently is no-one else. The brother did know that Mr. Force’s wife was dead and they had no children. He didn’t provide any other information.”

“How do you live almost eight decades and have no one? Sherman says. “So basically, we don’t know much about this guy. Does he have an advance directive?”

“Not that we know of,” Peabody says. “The social worker went with city police to his condo, but they didn’t find anything, an advance directive or a living will. He didn’t have much at all, no papers or books, just basic furniture.”

“First put the DNR in place,” Sherman says. “And let’s do an MRI. It will give us better data on the damage to his brain stem.”

“We can’t,” Peabody says. “I noticed the scar on his knee. We x-rayed his leg and he has three staples nailed into the bone; probably used to tighten loose tendons.”

“Then let’s get another CT scan,” Sherman says, “and contact the ethics committee. If the scan shows no improvement, I see no reason to expect any and no reason to continue aggressive treatment. We’ll hold an ethics consultation next week to discuss withdrawing care.”

“Don’t forget, for the DNR, we need another doctor to confirm he won’t recover and then we need approval of two non-physicians from the ethics committee,” Peabody says. “How do you want to handle it?”

“You take care of it, Dr. Peabody. I never understood the need for that policy,” Sherman says. “It should be my responsibility. I’m the best judge of his medical condition, not some DNR panel of non-physicians.”

“It’s not a hospital policy,” Peabody says. “It’s a state law.”

In another instant, what seemed like a whirlwind of activity was over. My head is spinning and I feel nauseous, like I’m hung over. A stroke, ventilator, CT scan, ICU; this is a hospital. What happened to me? Why don’t they know I’m here? Paralyzed, Unresponsive, Comatose? They’re talking about me like I’m some inanimate object, a specimen on a microscope slide. I am alive. Why can’t you see?

What’s that noise, an alarm? Who’s this by my bed? There’s a high-pitched whine in my ears growing louder. It feels like a whistle breaking through a pin hole, but it’s widening and the sound is growing fuller. What is happening?

“His blood pressure is spiking,” a woman says. “Why would that happen?”

“I don’t know,” another says. “Just give him an extra dose of propofol.”

I feel her pull on a line entering my wrist. The pain radiates up my arm; and the cloud in my head begins to gather again. I hold it off. Calm yourself. Assess the situation. I can’t. It’s too hard to think. Panic keeps surging. I have to resist. What happened to me?

Concentrate on here and now. I feel points on my body where things are attached, presumably linking me to the machines I see with my peripheral vision; the same ones that are chirping and beeping. Maybe I could send an SOS. Was that meant to be funny?

I’m talking to myself. Of course, I am. No one else can hear me; my oh my, if Daria were only here. But she’s dead, I think. Yes she is. Where’s her Phi Beta Kappa key? It helps me stay calm. She never took it off, never. It should be on my key ring. I always have it. But where is it?

Focus. I have to focus. There’s not much pain. But I’m so weak. I feel them touching me. I feel the breathing machine, and tubes channeling liquids into my blood stream. How unusual that I feel the liquids mix with my blood. When they enter it’s like a gust of wind hitting your face when you open a door to go outside.

Keep your focus. I keep drifting. Someone’s standing over me. No, don’t shut my eyelids. I need to know what’s happening. I need a reference point. They pull back the covers. It’s cold.

“The chart says L802 gets a sponge bath,” a woman says. “Look at those old age spots on his face and hands. You can have those removed, you know.”

“He looks like a wet rag that was left outside in the freezing cold,” another says.

“That’s how you look after a week in this place, when the mind goes the body gives up. You should have seen him the day after he arrived. We gave him way too much fluid and his body wasn’t clearing it. He blew up like a blow fish. Have you ever seen one of those? Well, we almost lost him. Now he’s beginning to shrink and shrivel. See how his hands and feet are curling up?”

Watch what you’re doing. That water feels like fire on my skin. There’s more pain as they dry me with a towel that scrapes like sand paper. They replace my gown and prop up the bed. If they’d lift my eyelids I’d be able to see the room; L802 she said.

I don’t know the time, but it seems like hours since that Sherman and Peabody were here. I briefly saw their faces. The older one, Sherman, has tanned tough looking skin like he’s been out in the sun too often, and jowls that remind me of Nixon. Peabody has the face of a patrician; reminds me of a prep school kid, too young to be a doctor. What must I look like?

I’m Wilbur Force, they said. Say it again, slowly. I’m Wilbur Force. I’m beginning to remember, but it’s so difficult. Everything’s all mixed up. Stay calm. Where is Daria’s key? I need something to hold onto.

Withdrawing care? Is that what I heard? How can they decide so fast? I just arrived. Who’s here now? Please oh please open my eyes. There, that’s better. Who are you?

“I’m the hospital chaplain, Morgan Chu. How are you this evening?”

Can she hear me? No, I can’t say anything, nor move. Did she really ask me how I am? Does she expect an answer? Maybe she knows I’m alive.

“I heard what happened this morning with Sherman. Winston told me. Harold Sherman’s the attending physician in this ICU and Winston Peabody is the fellow. You should know that Sherman’s been here a long time. He’s seen most everything, except maybe someone like you. That business about the DNR; Sherman knows there are procedures. The hospital slapped him on the hand just last month for not following them. And it seems to me a little early to talk about withdrawing care; that’s what Winston says. He will take care of you, and so will I.

“They say you can’t hear me, but I’m going to keep talking to you. It can help people in a coma. If I keep talking and you can hear me even a little it may help bring you back. I have to try. You see, I know you. I recognized you the day you arrived and I’ve been talking to you every day since then. I haven’t told anyone else yet.”

What is she saying? I don’t know this woman. I see her. She’s older, maybe in her 60s, a bit heavy set. She has a nice smile. It’s soothing. But I don’t need a chaplain. Maybe I’m just not thinking right. Here I go again, I’m fading. I’m tired, disoriented. Don’t give in. Stay awake.

“Do you remember me? I was a student of yours long ago. You were my ethics professor at Westminster College in Pennsylvania, near Pittsburgh. You’re the reason I work in a hospital. You specialized in medical ethics, working with doctors and their patients. I was an intern of yours one summer. I loved working with you. After I saw you, I Googled you and learned you retired about a year ago. The story said your wife, Daria, died a year before you retired. I was sorry to hear that. My husband died three years ago.”

If I could only signal her; but even if I could, I’m not sure I have the strength. She’s brushing my hair back from my forehead; looking right into my eyes. Blink, please, please let me blink. She has a calm face with smooth cheeks, wrinkles around the eyes, and a droopy neck.

I was an ethics professor at Westminster College? My thoughts race back and forth through time. I’m thirsty. I’m hungry. I’m trapped. I’m scared. I’m Kant; no, no I mean I know who Kant was. I used to tell the doctors, ‘Read a little Kant with your Gray’s Anatomy and show your patients some respect.’

What is this? I’ve no sense of time. Is the chaplain still here? She moved. I can’t see her. There she is. Now what’s she saying. She’s talking to me again.

“Winston is a good soul. Sherman’s been here too long. He should retire. He’s too cynical. He’s soured on this place and all the poor people who end up here. That’s who mostly comes in here; patients with nothing, most of them near the end of their lives, and they’re not as old as you might think. Most are in their 50s or 60s. They’ve led hard lives, and by the time they arrive here they have multiple chronic problems. Work in this place for a few years and you see what poverty does to a person. Sherman’s contempt for them is palpable. He’s from a different era.

“Winston understands people. He respects them. There was a middle aged woman in the medical ICU last week, a crack addict, whose weekend binge burnt out her pacemaker. The cocaine causes an arrhythmia in the heart every time you take a puff, I’m told, and every time it did, her pacemaker fired to correct it. It just fired too many times. Most residents, the younger ones in particular, said she shouldn’t get another. Why should taxpayers support her habit? Winston didn’t agree. He said the woman deserved another pacemaker and needed treatment for her addiction. You would like Winston. He reminds me a little of you.”

Things change so quickly. I must try to get control of my emotions; fight off the fatigue, sweep away the panic. What do I look like? What did they say a frozen rag? I feel more like a mannequin. I was a sophisticated looking gentleman, that’s what Daria said. She used to say, “You’re so charming, so calm, and so confident.” I can hear her. Help me, please.

“I’m going to watch out for you Professor Force. You know as well as I do for someone in your condition a DNR order is code for Do Nothing Really. The nurses all know it. They slow down, don’t attend to you. ‘The DNRs are dying,’ they say, ‘they won’t recover, let them go. It’s what’s best.’ The doctors send the signal the end is near. The DNR order let’s everyone know you’re terminal and withdrawal of life support is near. If the medical team is lucky, you’ll code before the order to shut down life support. It’s easier on the doctors and nurses than having to put an end to you.

“But don’t you worry. The nurses know I know. As long as I’m on your case they’ll behave. They know I’ll report anything I think is wrong. I’ve done it before. You taught me well. They think I’m a little crazy, the way I carry on with patients.

“It’s what I call my narrative theology. I get patients to talk about their lives so they understand how they came to be in the hospital. There was a young man in his 30s in the medical ICU, dying of liver failure. He couldn’t understand why something like that would happen to him. He thought he was too young. But he was an alcoholic suffering from cirrhosis. Since he was a child, he partied with his parents and their friends, including drinking alcohol. They partied every day. It never occurred to him that was wrong and that he drank too much. It was just how his parents lived.”

Outside my room a speaker is blaring code blue. The chaplain says good night and runs out. All the commotion seems to be a few doors down. An image flashes in my mind. It’s a violent encounter; nurses take turns pounding away on a person’s chest to restart a motionless heart. Ribs break, blood oozes from the corner of a slackened mouth, time of death is called, a sheet is pulled over the corpse and the room empties as quickly as it filled. What becomes of a body with no one to claim it? What is to become of me?

Listen to that. It’s a couple of bars from Brahms’s lullaby. I’ve heard that too. It’s a baby, born on a happier floor. One bows out, another debuts. The balance of life and death; one person making room for another or maybe it’s a cosmic Panglossian spoof in the midst of such despair. All is right with the world. Where did that come from?

Somebody help me. There has to be something they can do, if I could only tell them. What if I’m really trapped inside my useless body, a carapace of a dead man, with no way out? Would I want to live? Let’s end it. No, I’m not ready for that. It’s too soon. I need time to process what’s happened and what’s happening now. It doesn’t seem real; to be aware of what’s going on around me, but with no way to communicate.

I hear the nurses say ‘have a good weekend’ as they leave the floor. I wish the chaplain had closed my eyelids. I doubt I’ll get much sleep with shadows of people passing by dancing off the ceiling, competing for attention with my thoughts. Why can’t I just will myself to stand and walk out of here?

I’m not sure when I’m thinking straight. The panic ebbs and flows. I know I’m claustrophobic, but I have no sense of that now. It’s not as if I’m trapped in an elevator or locked in a discarded refrigerator. I experienced both, the elevator as a young adult and the refrigerator as a child. It was terrifying, not knowing if anyone would find me. The images and feelings flood back like they were yesterday. But this is different. I’m on the inside looking out like I’m stuffed in a fish bowl and no one sees me. Am I going mad?

My thoughts parade in words, images, sounds, smells, and emotions across a screen in my mind; mistakes, successes, shame and confidence. It’s as if my brain is rebooting after being shut down and I’m re-cataloguing everything. Let these thoughts find their place on their own. They are distractions. I must concentrate on how to get out.

But the memories keep rushing toward me. When will they settle down? I’m trying my best to focus. I was never as strong as I should have been. Maybe I deserve this. What’s this now? My inadequacies as a student, professor, husband. Go away. If I let them engulf me, will I forget them finally? I’m too weak to fight.

Is this what I have to look forward to, nothing but a mirror of my past? If that’s all I have, why live? Why would anyone want to live with nothing to do but remember? I miss Daria. All these emotions churning about, it must be the shock of the stroke. I wish that annoying Sherman and affable Peabody were back sparing over my care. Morgan’s voice is caring. My backside is aching.

Try to remember what happened. They said I’ve been here eight days. I must have been unconscious; or partially unconscious until today because I remember hearing a stream of voices. I couldn’t understand what they were saying. They must have been the doctors, nurses and this chaplain. It was like a radio signal fading in and out.

Concentrate. How did I get here? I remember walking through a park. It was early. I enjoy the morning when the sun breaks over the horizon and there’s no one around. The city sounds are silent. I hear the birds calling out as they awaken. It always makes me think of new opportunities. The sun was bright. My knee hurt more than usual. I stopped to rest. I don’t know how far I walked, but I was perspiring heavily. I was thinking something must be wrong. My heart was pounding too hard. It sounded like a drum beating. I was dizzy. I stumbled. I fell. I don’t remember hitting the ground; just stumbling.

I’m going to try to sleep now. Maybe this is a dream and I will awaken soon.

Isolation

Someone opens the blinds. The sound startles me. How long was I asleep? It must be morning. The light pours in. A TV is on again. Why? They think I'm comatose. I'm still propped up. I see most of my room. This is no dream. I'm locked in my body. The streaming memories have slowed. My thinking is more measured. I'm more awake than yesterday. Whoever's in the room, look at me. I am alive.

There he is; a rail thin boy, a teenager I guess, looking into my eyes. Take a good long look. You must see me. He's so close I smell the awful odor of cigarettes. But no, don't leave. There must be something I can do to make you realize I'm here.

He's putting more ointment in my eyes, and closing the lids. The lubricant is soothing. I won't complain this time about the darkness. There's no use. No good will come of panicking. I'm not going anywhere. I hear, feel, smell and see. I hear his footsteps. He's gone.

I have all these tubes and lines connected to machines performing my bodily functions, assessing my physical status. Are they keeping me alive? Surely they detect I'm here. I know what a CT scan and EEG are. But they took them when I was unconscious or nearly so. I'm back. Don't leave me in here. I feel invisible, person after person passing by without so much as a sympathetic glance. It's as if I'm homeless, standing on the street corner shouting for change. No one cares to hear me. I've been on the other end; a spurner. The beggar shouted back, 'What goes around comes around.'

Who's this now? "Time to clean up a bit, honey," she says. "You're going for another CT scan this morning." She sticks something in my mouth to the back of my tongue. It sucks mucous from my throat. It makes me wonder what would happen if they forget this procedure one day. Will I drown in my own sputum? She wipes my face and neck with a sponge. Daria used to do that when I was sick, carefully in a gesture of caring reassurance. This is rough and mechanical, the sponge scratching across my whiskers. What must I look like?

The lid on my right eye retracts about half-way, so I can see a bit. Three people come into the room and I'm being moved. "Where are you taking him," Peabody asks. "To get the CT scan you ordered yesterday," a nurse says.

That's encouraging, Peabody is still around. I hope Morgan is right, that he'll look out for me. Before we leave my room, they disconnect my bedside ventilator, reconnect me to another one, and transfer me to a gurney. The switch is brief, but I feel my lungs gasp for air. Can I breathe on my own? The sensation as they pick me up is startling. I'm not stiff. It feels like my vertebrae has collapsed, my aged body drooping between the hands of the orderlies. It hurts. They squeeze and jerk me much too hard. My bones will break. On the gurney, they push me into the hallway and disappear.

It's chiller here than in my room and brighter. It smells different, like a gymnasium that has just been cleaned with a lingering odor of human sweat. People rush past. I feel the draft; hear their labored breathing. I'm on my back, so I can't see much. An older woman, a nurse I suppose, looks down at my face with my one eyelid half raised. She looks repulsed. She wheels me around and we are on the move. I wish I knew how I looked. We move through big doors, go down a hallway and stop. We're waiting with other people for an elevator. My left eyelid rolls up a bit. I'm not sure how far. It startles a white coated young woman.

“What’s wrong with him?” she asks. “Stroke; he’s been in a coma more than a week,” my nurse says. “They want another CT scan. I don’t know why. It’s a waste of time and money, if you ask me. He hasn’t moved a muscle. He looks brain dead to me. Poor old guy doesn’t have anyone. That’s what happens when you don’t have kids. You end up alone.”

“What’s with his eyes,” the younger woman asks. “I’ve never seen them frozen like that. He looks as if he knows what we’re saying.”

I do know what you’re saying. If only I could move them or cry.

“See you,” says my nurse. “Hey, I hear you’re dating Winston Peabody. He’d be quite a catch, smart, handsome and rich.”

“Was dating Winston,” the younger woman sighs. “He’s too serious, too wrapped up in being the next great neurologist. No fun, if you know what I mean.”

“Who cares,” my nurse says, “with his bank account you make your own fun.”

We leave the elevator and move into what looks like the lobby of the hospital. People everywhere and I sense them staring at me like rubberneckers passing a highway accident, trying to spot the injured; schadenfreude, if you know what I mean. Avenue Q was the last play Daria and I saw before she died. We used to love strolling in New York in early December when the Christmas lights are everywhere, and you stop by a street vendor for a bag of hot, roasted chestnuts. There’s a good thought, and it didn’t come on its own. It was one I summoned. I’m more and more aware, almost normal if that’s possible.

When we get to the CT scan room, my chauffeur parks me in the hallway. I lie there for what seems like hours. Then they move me in for the scan. The attendant injects something into my IV. I know what this is. It’s dye so they can have better contrast for my brain activity. The attendant is talking to me. “You may feel a hot wave wash over you from head to toe as the contrast dye moves through your body,” she says. I guess they didn’t tell her I was unconscious. She and two male attendees pick me up from the gurney and place me on the table, positioning my head in the machine. They are much gentler than the orderlies in my room. Surely this will show I’m alive.

Back in my room I’m tired, anxious, and panicky again. But I’m holding my own, keeping my focus on the present. It isn’t easy. The scan will confirm my existence. I’m certain. I’m feeling confident. I heard someone on the elevator say this is Compassionate Care Hospital. It was the answer to a query from a man lying on a gurney next to me. “Just out of surgery,” he said. “I forgot where I was.” How I envied him and the words he spoke.

As the sun sets, a nurse is sponging my back. It smells like medicine. The liquid is too cold this time and I feel as if I’m shivering. Would that be a signal? Before the orderly leaves, he turns me on my side so I’m facing the door. The orderly does not see my open eyes, or doesn’t care. No need to look too closely at a vacant body.

My back wiped and hospital gown restored the orderly leaves and in walk Peabody and Morgan. The first thing Morgan does is open both eyelids. “There,” she says.

I feel less isolated. She and Peabody sound like they’re continuing a conversation.

“I’m concerned about this patient,” Morgan says. “You know what happens when a DNR is logged in his chart. The nurses will ignore him. It happens all the time, especially to patients with no family and friends around. Sherman’s preparing for the final act, withdrawal of the ventilator. I have an idea.”

“Why so much concern for this patient?” Peabody asks. “You’ve spent time with him every day since he arrived.”

“I can’t say right now,” Morgan responds. “Have you heard what they’re doing in the surgical ICU?”

Peabody is unresponsive.

“One of the attendings there believes strongly in using what’s called narrative medicine techniques with her residents to help them think about their patients as people. It’s similar to what I do in getting patients to talk about their lives and their illnesses. It helps them understand the full scope of what’s happening to them. In the case of narrative medicine, the physicians express their feelings about their patients and the care they’re delivering.”

“How do they do that?” Peabody asks.

“They keep a parallel chart, writing down their thoughts, nothing clinical though. That’s why it’s called a parallel chart. It’s their feelings and opinions, things you can’t put in a patient’s medical chart.”

“What do they do with the charts?”

“They share them with each other,” Morgan says. “It gives them a chance to understand their work from a different perspective. I want to write a parallel chart on Wilbur Force. He’s alone and can’t communicate. He’s the most vulnerable kind of patient. Sherman, the residents, the nurses, and even you I think, have written him off. None one thinks he’ll recover.”

"How will writing a parallel chart change anyone's perspective?" Peabody asks.

"I'm writing how I feel about the patient, my impressions," Morgan says. "There's no reason a chaplain can't benefit from this exercise. We're part of the medical team. I'd be willing to share it with everyone. They may benefit from a different viewpoint. Everyone is so busy. No one stops to really look at who's lying in these beds."

"You're an optimist," Peabody says. "Sherman, for one, has little patience for people in Mr. Force's condition. You know Sherman; he calls himself a compassionate libertarian, with the emphasis on libertarian. Wilbur Force lost claim to any more of society's empathy after he collapsed on the street. He's 77; on Medicare; no family to speak of; unconscious with no hope of recovery. He's done as far as Sherman is concerned. He should have died in the ER."

"Surely, you can't believe that," Morgan says.

"No, I don't," Peabody says. "This is Compassionate Care, and I take the name and mission it implies seriously. Except, what can I do? Sherman's the attending physician. My career depends on his assessment of my fellowship. You better watch out too. I remember what happened when you wrote in that elderly woman's medical chart that she claimed she was being sexually abused in the medical ICU."

"I wanted to alert the staff to the patient's concerns," Morgan says. "I acknowledged I wasn't sure she was telling the truth. As it turns out she wasn't, but the psych folks determined she likely was recalling abuse she suffered as a girl. I thought the physicians and nurses would have thanked me for helping them understand her anxieties. Instead, I was made to feel I did something wrong. A parallel chart is different. I know this sounds trite, but I look on it as a way to get in touch with my feelings about what we're doing here and give Wilbur Force a voice."

"What do you hope to gain?" Peabody says.

"I don't know that I'll gain anything. Maybe I can convince you and the residents to try," Morgan says. "With patients like Wilbur Force, we should take extra care. It's too easy to forget he's a person."

"Good luck," Peabody says. "We'll have results of the latest CT scan for Monday's rounds. But don't expect much. I believe he suffered severe damage to his brain stem from the stroke. This guy is a quadriplegic for good and he's comatose. Even if it were possible for him to regain some level of consciousness, we don't know how long it would take; and I doubt he would survive without the ventilator. Who's going to take care of him? No nursing home will take him. We can't keep him here. Are you crying?"

"I'm just tired."

"It's getting late. I have to go," Peabody says.

"Wilbur Force's brother decided to visit," Morgan says. "He's already told us he wants no responsibility for his care. I'm not sure I should try to convince him otherwise. They've been estranged for many, many years. He clearly is not in a position to know what his brother would want. Can you be here to talk with him?"

"What time is his brother coming in? Maybe I can stop by."

"He's due in from Detroit about 2 pm."

The night shift is settling in. The lights are turned down in the ICU. Morgan is still standing by my bed when the orderly comes in to turn off the TV, close the blinds and shift me on my back side. It’s the same teen-ager from earlier. He reaches out to close my eyes, but Morgan stops him.

“I’ll close them when I leave,” she says.

“I don’t know how you stand it. It’s unnatural.”

As soon as the orderly goes, Morgan starts talking to me, pausing now and then as if waiting for someone to translate. “I won’t abandon you. Last year we had a sociologist in here looking through files of comatose patients with no family or friends. He wanted to see how the patients were treated. There were about 100 like you over the course of 10 years. One hundred people without anyone to speak on their behalf. The sociologist discovered the medical teams cut corners. It’s not surprising. It’s natural to concentrate on patients who communicate or have families watching out for them. Who’s going to care about someone like you?”

Morgan’s voice trails off at the end. “I hope you don’t mind me visiting you every day and talking like I do.”

She closes my eyelids and leaves. I’m not sleepy. I have too much to process. Peabody’s prognosis of my condition is disturbing, but at least now I know some more about what I’m facing. But how can it be that I can think and they not know. I’m completely isolated.

I continue to gain control over my thoughts. That’s a relief. I have more clarity, and sense of purpose, as long as I can keep the panic at bay. It’s not easy, I can tell you. I’m getting a better feel for how I think. But I need more time to explore. I remember more about who I was. But who am I now that my body doesn’t work. All I have are thoughts.

The notion of a mind hovering somewhere above flesh and blood, independent, made no sense to me before this, and certainly doesn’t now. But I would gladly have foregone the experience of confirming it first-hand.

It’s so clear. Everything about me is connected to everything else that I am. In my stillness I sense a scaffold of bone supporting tissues fed by veins and arteries covered in skin. I never much dwelled on how my body worked. It seems ironic I would be more aware of all the different parts now that I’m immobile. I’m a statue brought to life for an audience of one; a scarecrow with a brain. I may not be able to move or smile or touch but I can think; that’s something. A student once asked me, ‘What would be worse, losing use of your body or losing your mind?’ Well it’s obvious, isn’t it? They are one in the same. You are forever changed. To survive I will have to reinvent myself. But that doesn’t seem possible. I can’t. I’m stuck in space, like a lone fly, isolated, buzzing about in a box car with no control over where it goes.

Anger

Who’s talking? Two women, nurses I think, are in here before sunrise arguing over something. My sleep is intermittent; not surprising given the anxieties that crawl back and forth across my withering corpse like so many insects preparing to feast. There are also the occasional sharp pains that erupt from different regions as if parts of my body are trying to break out of lock-down. I want to strike out with every molecule of energy to alert my new found associates to my condition. If I am to die in this bed, I will not go quietly.

I can't understand much of what the nurses are saying, but I hear Sherman's name. One pulls open the shades to let in the early daylight. Now a third person is in the room. He lifts my eyelids and peers in, shouting. "Hey, blink for me. Is anyone in there? What's with this guy?"

"What are you doing here?" the younger of the two nurses says. "We have to clean him up and change his sheets. What's in the syringe?"

"Peabody left instructions in his chart to continue a medication to keep his blood pressure under control; just following orders."

"Well, hurry up so we can make him presentable," the older nurse says. "The chaplain left us a note last night his brother arrives this afternoon."

I feel the medicine push my thoughts into a blur. I'm still aware, but dull. I'd say lethargic, but then given my condition, I can't be anything but.

With all these people peering into my eyes, pinching me, shouting commands to move this or that, surely they should realize there is someone inside this sack of skin. Undo my straightjacket and look inside, I cry out. How ignorant can you be?

After yet another sponge bath, one of the nurses yells into the hallway for Kelly. They leave me naked on my side facing the door. A giant of a man approaches. He ducks to keep from hitting his head on the door frame.

Kelly, an orderly I'm guessing, picks me up and cradles me in his arms a couple of feet above the bed while the two women hurriedly change the sheets. It's humiliating; being held aloft naked as if offered up for all to see what a useless person I've become. I was always shy about my body. I wasn't overweight, but I always felt self-conscious at the beach. The nurses could have put a new gown on me before Kelly got his morning workout, but they aren’t thinking about me. They see only a body taking up space in their ICU.

With Kelly departed and with me safely on clean sheets, the two nurses resume their heated discussion. The younger woman says she overheard Sherman talking to Peabody about finding more patients who are unconscious and dying for use in a drug trial.

“Winston, who is pretty even tempered, freaked when Sherman said he still needed more patients who didn’t have families to interfere. Then he changed his tune. Sherman mumbled something I couldn’t hear. I couldn’t believe it. Winston said he’d check around in the ICUs; Winston Peabody, of all people. He’s more honest than an Eagle scout.”

“He knows enough not to challenge Sherman straight away,” the older nurse says. “Sherman can have him reassigned in a heartbeat.”

“We have to report this,” the younger woman says.

“Don’t you do it,” the other one warns. “The supervising nurse for the ICU is an old friend of Sherman. She won’t believe you. Let Winston work this out. Does he know you overheard them?”

“No, I don’t think so. I was in here with him and they were standing outside his room. They didn’t see me.”

I drift off after they leave. I don’t know how long I was asleep. Sometimes my thoughts are so clear, other times I’m unsure. I’m certain of the image in front of me now. It’s my brother, Watson, and he is standing with Morgan. They look down at me. Watson is my older brother by seven years. He should be lying here instead of me, the old coot.

We haven’t talked for years, and even before then we were never close as adults. All communication ended in our fight over care of our dying mother, who was comatose and in need of a kidney transplant to survive. I remember it like it was yesterday. Watson wanted to challenge the hospital’s refusal to place her on the transplant list and keep her alive until a donor was found. She also suffered from diabetes mellitus. I agreed with her medical team and since mother identified me as the decision maker, my opinion prevailed. Our father had died several years before. Watson castigated me as an Ivory Tower professor practicing philosophy on our mother. He was right, I suppose. The prevailing opinion of the day was to do everything to keep patients alive; but her doctors and I agreed there was little hope she could survive very long even if a transplant were successful; better to save those resources for younger folks with more productive years in front of them. But I also felt mother would not want to prolong her life. She never told me that, it just seemed to make sense. I’m not so sure now. On the other hand, I have a whole new perspective.

Watson never forgave me when mother died several days later. ‘How can you stand here and watch her last breath?’ was the last thing he said to me before leaving. It was a gasp, as I recall.

“I really want nothing to do with him,” Watson tells Morgan. “I just came to see for myself what he looks like helpless. He was always so independent. We are so different. I was popular believe it or not. It’s a curse of getting old. You lose your connections with people. Nobody cares anymore; out of sight, out of mind. You’re no longer part of the conversation. I used to command a fair bit of attention. I had a lot of fun in my day.

“Wilbur didn’t care much about that. He was always so serious. He worked hard in school, always championing some new cause; always doing the right thing. He told me it was his destiny. His destiny, do you believe that? He said his destiny was in the name our parents gave him, Wilbur. Our ancestors were English and there was an 18th century hero named William Wilburforce. He spent his life fighting slavery. Eventually he won, forcing an end to the practice in Great Britain. Wilbur made the whole thing up, of course. He was five. He said our parents named me after Sherlock Holmes’s sidekick. Can you believe that? He was reading Sherlock Holmes books at five. I haven’t thought about that in ages. He was creative, I’ll give him that. I never understood why he ended up at that small university. I don’t even remember its name. It’s all so very long ago.”

“The name is Westminster College,” Morgan says. “He retired a year ago. It’s a small liberal arts school, and well-respected.”

“I may sound sentimental reminiscing about our childhood, but I can’t forgive him for letting our mother die,” Watson says. “After all these years of resentment, it’s part of who I am. He’s on his own. How long does he have?”

“As I told you over the phone, he had a stroke that damaged his brain. As you can see he is completely paralyzed. They think he’s in a coma and will not regain consciousness. He hasn’t moved a muscle since he was brought here from the emergency room more than a week ago. His eyes are open, but he hasn’t moved them or blinked. Another CT scan was ordered and we will have the results tomorrow. If it doesn’t show any improvement, the attending physician, Dr. Sherman, is likely to withdraw treatment. The decision could be made this week.”

“Maybe I’ll hang around for awhile,” Watson says. “It’s not like I have anything pressing. I’ve nowhere to go and no one waiting. At 84 you slow down. At least I’m healthy. Besides I’ve never been in this city. I’d like to take a look around. You have my cell phone number. Call me if he takes a turn for the worse? I’ll probably leave in a day or two if I don’t hear from you.”

“Before you leave I feel I must tell you something,” Morgan says. “I know you’re brother. I was a student of his at Westminster 40 years ago. I haven’t told anyone else. Seeing your brother after all these years has startled me. He is the reason I became a hospital chaplain after becoming a Presbyterian minister. I took two of his ethics courses. He was brilliant, and I admired him so much. He was only 10 years older than me. I thought he was such an amazing human being.”

“I’m not sure what to say,” Watson says. “Are you saying you have feelings for him? It seems a little creepy to me. What do you intend to do? What do you want from me?”

“Nothing,” Morgan says. “I don’t want anything from you. I guess I wanted to tell you I’ll look out for your brother. I know what happens to patients in his condition. It’s just a matter of time and not much of it, before they withdraw treatment. I suppose there’s nothing else to do. It’s not right, if you ask me. We’re not equipped to handle patients like your brother.”

“That’s no concern of mine. I came here to bid good riddance. My mother didn’t have to ask Wilbur to make her life and death decisions. I was the older one. She could have given me that responsibility and maybe I would have had a little more time with her. I took it as an insult and it still hurts. If you want to know the truth, I blame my brother for my mother’s death. He should have demanded every treatment to keep her alive. You never know when a miracle will occur.”

I always thought my brother was ambivalent towards me, especially after he returned from the Army. I didn’t realize how much he dislikes me. He used to take care of me when we were kids. We got sick together, the measles, mumps and flu. He always made me laugh. That all changed after he went to college and then was drafted. He was never the same. Something happened to him in college. It involved a girl, but I never learned what it was. We weren’t a rich family, but Watson was always asking our parents for more money. They just didn’t have it. We were all so proud when he won a full academic scholarship. I don’t know how he lost his way.

After Watson leaves, Morgan stands next to my bed and holds my hand in both of hers. She kisses me on the forehead, closes my eyelids and leaves. Nighttime descends on the ICU. I’m not sure how I feel about Morgan. She strikes me as odd, I suppose, but then again, maybe she is my best hope, for what I’m not certain.

Helplessness

I awake to the feeling of a rush of something entering the blood stream in my arm, pushing through it like an ocean wave at high tide inching further and further onto the beach. My thoughts clear away the darkness of sleep, but I don’t know what the nurse standing next to me administered. Not knowing what’s being shot inside me adds to the anxiety as I wait to see how it affects me.

Peabody walks in and asks the nurse, “Did we get the results of the weekend CT scan yet? I want to take a look before Sherman starts rounds this morning.”

“Not yet,” she says. “It must have been a busy weekend.”

The nurse’s voice sounds new. “Open his eyes and moisten them with the drops, but close them again before Sherman gets in here,” Peabody says.

“What’s going to happen to this guy?” the nurse asks. “I wasn’t here Friday, but it doesn’t look like he’s improved from when they brought him in. I understand his brother was here this weekend. But it says in the chart he wants nothing to do with him. You know what that means, fast track to the morgue.”

“Sherman already asked for an ethics consultation to discontinue treatment. We should take more time to assess his condition. But it’s probably not worth the effort. You just really don’t know. If I was asked, I’d say it’s probably 80 to 90 percent certain he won’t recover,” Peabody says.

I need a plan, but I have no plan. I’m a prisoner with no one to discuss my defense. These people can’t do whatever they want to me. I won’t let them. As the frustrations intensify, the pressure builds inside my head making me feel as if my skull will crack. Can I hold it together? I worked with patients facing death and I know how their families struggled to understand what was happening. How many times did I urge them to think about what their loved one wants. They had no idea as it turned out. I see that now. Well I know what I want, I guess. I’m not ready to die; or maybe I am. Maybe Sherman’s doing me a favor. What life could I possibly have not being able to move? Moving about is essential to me. It’s who I am; who I was. Who am I fighting, these people or who I’ve become? My sight is gone. Sherman must be coming.

The mixture of voices and shuffle of feet gather outside my door. It’s odd, but it seems my thoughts change depending on whether I can see or just hear. They seem more introspective when I can see.

“Where are we starting this fine Monday morning? Let’s get on with it,” Sherman says.

“L802, the stroke victim who’s unconscious and unresponsive, but stable” someone says.

“How long has he been here?” Sherman asks.

“Ten days” the other voice says.

“Now I recall,” Sherman says. “Did we get the code status fixed?”

“Not yet,” another voice says.

“Where is Dr. Peabody?” Sherman asks.

“Here he comes,” yet another voice calls out.

“Morning Dr. Sherman, morning everyone,” Peabody says. “The results of the CT scan are in the computer.”

“Let’s take a look,” Sherman says. “I don’t see any change; nothing new here to suggest any awareness. It seems clear there’s no sign of improvement to the brain stem. Does anybody see anything else? There’s nothing to suggest to me he is likely to recover.”

“I agree, it doesn’t look good,” Peabody says. “But it’s still early yet, isn’t it? We haven’t withdrawn the sedatives to see if he can breathe on his own or if he is responsive to any external stimuli.”

“Well go ahead and do it,” Sherman says. “But let’s get the ethics consult set up. What does this guy have for insurance?”

“Medicare,” Peabody says, “but no supplemental.”

“That means the hospital gets shortchanged,” Sherman says. “What about the DNR?”

“I haven’t had time,” Peabody says. “We need a reason for implementing the order. Which one of the three boxes on the form do you want to check?”

“Check the box that says further treatment is futile and resuscitation would be harmful for the patient,” Sherman says. “And get Kopeckne to sign off.”

“I think we should wait for the ethics consult,” Peabody says.

“It’s your call Dr. Peabody. Come on people. Let’s keep moving. Who’s next?”

The voices and the footsteps disappear. They didn’t come into my room this time. I can see again. It’s so hard to judge time, seems like I fade in and out. Now Peabody’s standing over me. He must have opened my eyes. Morgan’s standing next to him.

“Sorry I couldn’t make it yesterday,” Peabody says. “How did it go with the brother?”

“He’s bitter,” Morgan says. “He’s been holding a grudge for years. Even if the brother wanted to make decisions, I don’t think we should accept his judgment. He’s too hostile toward his brother.”

“Did the CT scan show any improvement?” Morgan asks.

“Not that we could see,” Peabody says. “The brain stem appears to have been severely damaged. It controls voluntary muscle movement. That’s why he’s paralyzed and the fact he’s completely paralyzed is further indication to me of the extent of damage.

It doesn’t look like he has any chance of regaining movement of any kind. It’s more difficult to assess the upper regions of the brain to know if he has any level of consciousness or awareness, particularly after only a week and a half. But with no family or friends on his side, Sherman has enough medical evidence to support withdrawal. We are about as sure as we ever will be that this patient isn’t going to recover, and that’s enough for Sherman and the hospital.”

“What about me,” Morgan says. “I can advocate on his behalf. I thought withdrawing life sustaining treatment from someone like Wilbur requires court approval.”

“Oh, it’s Wilbur now? How much time have you been spending with this patient? Anyway,” Peabody says, “you know as well as I do, the hospital adopted its own policy for withdrawals. It takes too much time to get the court to appoint a guardian, and most of the time the guardian and the court side with the hospital. It’s a waste of time. The only thing you can do is make sure you’re in on the consult. You can have your say there.”

More commotion in the room; someone enters.

“Mr. Force,” Morgan says. “I thought you were leaving.”

“Yeah, well I had a change of plans,” Watson says. “I got a call on my cell from a Dr. Sherman this morning and he asked me to come in today.”

“How did he get your phone number?” Morgan wonders out loud.

“It would be in his chart,” Peabody reminds her.

“Oh, well…ah, Mr. Force, I want to introduce you to Dr. Winston Peabody. He is the fellow, the second in command, as it were, to Dr. Sherman on your brother’s case.”

Peabody doesn’t have time to extend a greeting before someone else jumps into the room. It’s Sherman.

“Mr. Force. I’m Dr. Harold Sherman. It’s good to meet you. I asked you to come in today to reconsider acting as a surrogate decision maker for your brother. Do you know what a surrogate decision maker is?”

“Yes, I do. My brother and I went through this when our mother died,” Watson says.

The four of them, Watson, Sherman, Morgan and Peabody, are hovering above me. My eyes are open and I’m on my back. I see only parts of each of their faces. What is Sherman trying to do bringing Watson back in here?

“Good,” Sherman says. “Although you have been estranged from your brother for many years, you are still in the best position to know what he would want in this situation.”

“Yeah, well I know what he did for our mother when she was in a similar situation,” Watson says. “He said she wouldn’t want to live that way, and the doctors let her die.”

But I’m not in the same condition as our mother I scream. She was in a persistent vegetative state, or at least that’s what they told us. And she was moved out of the ICU into a regular room of the hospital and was there for a month while we waited to see if there was any improvement. There never was, or at least that’s what they told us.

“Can you tell us why you don’t want to help your brother?” Sherman asks.

“Wait a second, Dr. Sherman,” Morgan says. “Watson made it clear he didn’t want to make decisions.”

“Well you are free to leave, chaplain, if you don’t want to help,” Sherman says.

Morgan disappears from view, but returns, standing over me.

“No, I’ll stay,” she says.

“Mr. Force,” Sherman says, “why don’t you want to help your brother?”

“I’ve been thinking about that ever since you called this morning,” Watson says. “And I think you’re right. I should take responsibility for helping my younger brother. In my opinion, he would never want to end up living this way.”

“And did he interact with people? Did he enjoy engaging in conversation?” Sherman persists.

“Yes, of course.” Watson says. “He was a college professor. Lying around doing nothing, unaware of what’s going on would be anathema to my brother’s personality.”

“Do you know if he had an advance directive?” Sherman asks.

“No, I don’t,” Watson says.

“Then based on medical evidence that indicates your brother is comatose and permanently paralyzed from head to toe, and will never recover consciousness, you think he would not want to live in his current condition. Is that right, Mr. Force?”

“Yes,” Watson says decisively without a hint of doubt.

“Dr. Peabody, make a notation in Wilbur Force’s chart that his brother, Watson, agrees to be the decision maker and in his opinion his brother would not want to live,” Sherman says. “We will want to have this information when the ethics consultation is held.

“One other thing Mr. Force; if we were able to wean your brother off the ventilator and stabilize his condition, would you be willing to take him home and care for him? He would need 24-hour care.”

“No,” Watson says. “I don’t have the accommodations or the money. I’m too old. I’ll probably need someone to care for me in a couple of years, if I live that long.”

“We know he can’t be transferred to a long-term care facility unless he has the money to pay for it. Does he have money for long-term care?” Sherman continues.

“No, not that I know,” Watson says.

“So even if you thought your brother would want to exist in his current state, there is no place for him to go when he leaves here,” Sherman says.

“That’s right,” Watson says. “He has no relatives other than me.”

“Dr. Peabody, make sure you note that in his chart as well.”

How did Sherman convince my brother to get involved? He’s never been decisive about anything. That’s one reason our mother chose me after dad died to serve as medical and legal power of attorney to make decisions about her care. She knew I would make them. There must be something else going on.

Thank goodness I never updated my advance directive. It identified Daria as my decision maker, but I didn’t detail specifics for withdrawing life support if I was unconscious. I forgot about it after she died. I trusted Daria to use her best judgment. If there was no chance I could recover, I knew she would let me go. Who could imagine a situation like this?

Everyone leaves, except this nurse. What is she doing? She’s injecting something into my IV line. I’m starting to panic. Maybe it’s a realization Sherman will get his way.

It’s as if I’ve been thrown into deep water with my arms and legs bound. I’m sinking, and struggling with all my might to get free and reach the surface, but I just keep sinking. Now I’m screaming as loud as I can. The fear is overwhelming, sweeping through every portion of my body, looking for an exit. Surely these people can see my skin expanding like an overfilled balloon about to explode. They must see it. They must notice my breathing is more rapid. My blood pressure should be skyrocketing. My heart is racing. How can they ignore me? I’m losing it. My world is collapsing. I can’t feel anything. Am I dying? Is this it…?

“We almost lost him earlier today,” Peabody says.

‘What happened?” Morgan asks anxiously.

What are these two doing here? What happened? I’m exhausted.

“Shortly after Sherman’s discussion with his brother, we took him off all medications to check if he would respond to verbal commands and to try weaning him off the ventilator,” Peabody says. “We gave him an antidote for his sedatives, but we must have given him too much. We almost lost him. We gave him morphine to counter the antidote. It worked. His condition is stable. But I’m hesitant to try removing the medications again. There’s really nothing to suggest he’s not in an irreversible coma. I know we can’t be 100 percent sure. But it’s unlikely he will recover, and the fact he has nowhere to go from here adds to the pressure to withdraw.

“I’ve begun keeping a parallel chart on Mr. Force,” Morgan says. “Remember our discussion? I asked the hospital ethics committee chair and the head of chaplaincy for permission. They approved it. Is it okay if I share my entries with you?”

“Certainly,” Peabody says. “I’m curious how this works.”

“Good. I was also thinking about something else earlier today,” Morgan says. “Sherman’s acting stranger than normal, don’t you think? He didn’t need the brother to empty Wilbur’s bed.”

“Maybe it’s his wife,” Winston says. “You know he’s on number 3. She’s much younger. The nurses told me they overheard him on the phone screaming at her that she owes him $20,000 for voice lessons. Apparently she’s an opera buff and convinced Sherman to buy her lessons from the director of the local opera company in town. After the shouting on the phone, one of the nurses followed Sherman to the office of his pal, Dr. Kopeckne, and eavesdropped. Sherman’s wife is leaving him. She told him the voice lessons opened up her creative side and she needs time to explore this new part of herself. Sherman hired a private detective who discovered her explorations included the opera director.”

“Jeez,” Morgan says. “What a mess. I kind of feel sorry for Sherman. But I think there’s something else going on.”

Morgan then passes a folder across the bed to Peabody. It’s hard to concentrate. Maybe it’s a residual effect of the mistake they made. I wonder if they’ll tell anyone. I keep seeing white splashes burst in my head.

“Take a look at that,” Morgan says. “It’s the first entry in my parallel chart. I wrote it before Wilbur’s brother arrived. Read it out loud so Wilbur can hear it.”

Friday, July 6, 11 pm, the eighth day of this patient’s treatment in the neuro ICU, room L802. His name is Dr. Wilbur Force and I know him… “What?” Peabody says. “How do you know him?”

“Just keep reading,” Morgan says.

He was my ethics professor in college. I recognized him as soon as I saw him in the ICU the day he arrived, June 29. How helpless he looks. It's difficult to see him this way. He presents a dilemma for the ICU, the hospital and the medical team; a man, presumably dying, with no one, and not dying quickly enough. What can they do with him? It's sad to hear myself say it. He has no one except a brother who's hostile toward him. He's vulnerable and alone in a place where everyone's too busy, pulled in too many directions, too absorbed in the next emergency and too used to death.

I'm praying for him. I've been talking to Dr. Force every day, and I'll keep on talking, trying to reach through his coma. I think he would appreciate it. I know I would. No one else will take the time. The ICU can be a cold, clinical place.

"I don't know how to react, Morgan," Peabody says. "This reads like he means much more to you than a former teacher. What do you intend to do with this? I'm a little worried about you."

"I want to give Wilbur a voice," Morgan says. "Somebody has to speak for patients like him. The ethics committee chair and my boss will be the only ones reading this. They'll decide if it's worth sharing with anyone else. But if you ask me, the medical team should appreciate knowing what someone else thinks about the challenges they face. There's nothing sinister going on here."

"It's getting late," Peabody says. "I have to leave. Do you want me to walk you to your car?

"No, I'm going to stay awhile and make another entry," Morgan says. "Have you scheduled the ethics consultation?"

"It's Wednesday afternoon at 3 pm," Peabody says. "Good night, Morgan."

I can’t see Morgan, but I hear her.

Monday, July 9, 9:45 pm, the eleventh day of Dr. Force’s unfortunate visit to Compassionate Care Hospital. I say unfortunate, for he is the most vulnerable of patients in any hospital; more vulnerable than a newborn, for even if the newborn were unwanted by her parents, there would be no shortage of hospital personnel to care for her. It’s natural. She has her whole life before her. This patient is at the end of his. His comatose condition essentially cancels his autonomy. Even if his brother wanted to be involved, if he truly cared about Dr. Force, I don’t think he’s qualified to make decisions. No one should make decisions for another.

Surrogate decision-making is fallacious, if you ask me. No one can know what another person wants. There has to be a better way.

When I look at Dr. Force with his eyes staring straight ahead, I’m not 100 percent convinced he’s unconscious. I’ll keep trying to reach him. I’ve witnessed too many mistakes that go unchallenged. God help me.

“Good night Wilbur.”

How could I not remember this woman with her sensitivity, empathy and courage? It’s obvious to me now whatever happens is out of my control. I always believed we make what we will of who we are, plot our own course, adapt to the environment and strive to improve it; make a difference by making society more inclusive and less exclusive. I am in a different place now, a different world, a different reality; no will of my own to do anything. I didn’t choose these people, but I’m totally dependent on them.

Agitation

Something doesn’t feel right this morning. I’m more anxious than I have been. I have to calm myself. Yet I feel a sense of panic building inside me and I can’t stop it. It’s as if my brain has a fever and it’s getting hotter and hotter. If I could move I would run and jump out of the window. I am screaming now as loud as I can, but of course no one hears me. I am beyond agitated. I’m frantic, my head is exploding. How can my thoughts be so vivid and I’m not able to move a muscle?

What’s happening now? They’re pushing something in my arm again. Please let it be something to help me. There, I’m calming down. I’m not so hot. Who’s talking? It sounds like Sherman and that older nurse.

“What are you doing? Sherman asks. “I’m giving him his medicines,” the nurse says. “I forgot to give them to him earlier this morning.”

“Please leave us,” Sherman says, dismissing the nurse.

Sherman is at the foot of my bed and he’s talking to another person who is standing in the door way. “Clean your hands and put on that paper gown and come in the room,” says Sherman, who now is beside me. I see a portion of his face.

All of a sudden a bald man shoves his face about six inches from my nose. He peers into my eyes. “Are you sure he’s unconscious?” he asks.

“Yes, yes, of course he is,” Sherman says. “He’s in a coma and completely paralyzed. He suffered a serious stroke about a week and a half ago. He’ll never recover. We’re holding an ethics consult tomorrow to discontinue his life support and let him die. As soon as I saw him last Friday, I knew we had our last patient. He fit the profile, incapacitated with no chance of recovery, and no family to interfere. We knew he had a brother, but we were told he wanted nothing to do with him. Then he shows up and I had to rethink our approach. We don't have time to wait for another subject. It's taken us two years to find the right patients to use. I decided it was too risky to proceed without getting the brother involved. He doesn't like his brother, but you never know. He could make trouble. He agreed to cooperate, as long as we paid him. Not much, thank goodness."

The bald man moves away from my face. He is still leaning over me and I see he's wearing a white shirt and tie, like a businessman. The smell of his cologne is nauseating. "What's this one's name?"

"Wilbur Force," Sherman says, "and his brother is Watson. He should be here shortly. He insisted on meeting you.

"Here he is. Watson, this is our benefactor, Mr. Clyde, Horatio Clyde," Sherman says.

"Damn, the change in humidity really makes my back hurt," Watson says. "I almost couldn't get out of bed this morning. But I wasn't going to miss this. So what are we doing to my brother?"

"We're not doing something to him," Clyde says. "He is helping us advance the science of the healing arts, as it were."

"You talk funny," Watson says. "Healing arts sounds to me like something a snake oil salesman would say. Just tell me what you're going to do him. It won't hurt him too much, will it? Although I guess I don't really care."

"Watson, we've been through this," Sherman says. "Your brother is in a coma. He's unconscious. He won't be harmed. He's receiving medication for pain. He won't recover. He’s going to die, whether it’s in a few days or few months. We’re giving him an opportunity to help you, me, and millions of other people.”

“Mr. Force, I discovered a revolutionary new drug for reversing brain damage caused by stroke. I’m quite proud,” Clyde says. “I took my discovery to a company and they funded pre-clinical trials in rats. The drug worked. I knew it would. It helped the brain repair a significant portion of damaged tissue, but it also damaged the rats’ livers.

“It killed the rats, you mean,” Watson says.

“Well, yes, I guess you could describe it that way,” Clyde says. “But we were able to show their brain function improved.”

“You still haven’t told me what you’re going to do to my brother,” Watson says.

“The company pulled the plug on the drug,” Clyde says. “They didn’t give me time to find out if it would work at lower doses. I know if I can get the right dose, I can show the drug repairs brain tissue and doesn’t damage the liver.”

Brother, please say something. Can’t you see where they’re going with this? Are you that dense? Or do you hate me that much?

“The company, NeuroWonder, returned the rights to the compound to me,” Clyde says, “and I came to Dr. Sherman for advice. He’s one of the leading neurologists in the nation. This is his idea, and I agree it is brilliant.”

“We’ve been testing dosage levels in people like your brother who are going to die anyway,” Sherman says. “Your brother is one of the heroes. He is helping the world find a cure for stroke victims. It’s historic when you think about it. How many times in our lives do we get the chance to make the world a better place?”

"I'm no medical professional, but if it's so heroic, why is it so secret, and why are you willing to pay me $10,000?" Watson says.

"We feel you should have something for helping us and we insist you tell no one," Sherman says. "Your agreement to withdraw life support from your brother when we meet with the ethics committee tomorrow will help ensure we can proceed with our plan. Let me be clear again so you have no concerns. He's going to die. He'll never recover. But we need to let him die within four or five days of giving him the drug so we can autopsy him and see if the tissue damage improved. During those four or five days, we'll also be able to judge the toxicity."

"I still don't quite get it," Watson says.

"We didn't want to do anything without your permission, of course," Sherman says.

"$10,000 is $10,000. I'm an old man and I'm not rich. I've never had much money. I didn't amount to much. I blame the Army for that. And everyone else I guess. Maybe this will give me some payback…for what he did to my mother."

"You're doing fine, Watson," Sherman says. "Your brother is the last patient we'll have to use to find the right dosage. We have tested 19 others just like your brother and we found tissue repair in each of them, but the liver remained a problem. The last woman suffered minor damage, just enough to raise a red flag with the FDA."

"What's the FDA?" Watson asks.

"It's the federal agency that regulates drug development," Clyde says.

“Watson,” Sherman says, “we think by lowering the dosage just a little more we will still get the same level of brain tissue repair without liver damage. This is a historic moment, and you and your brother will be part of it.”

“I’m in,” Watson says. “I’m convinced. The money’s right and I suppose helping people is a bonus. I’m certain my little brother would like it too, wouldn’t you Wilbur? When will he get the drug?”

“We have to wait until after the ethics consult tomorrow afternoon to validate the decision is made to withdraw life support. Then we’ll dose him in the evening,” Clyde says. “We’ve noticed a little spike in blood pressure when the drug is administered. We have another doc on board to cover for us. The spike only lasts about a minute. We’re not sure what that is.”

“How much have you paid this other doc?” Watson asks.

“It doesn’t concern you,” Clyde says.

I could never have imagined the depth of Watson’s contempt; that he would help these people. How could I have been so oblivious to my brother’s feelings toward me all these years?

There they go. I hear them leaving. How can Sherman get away with this? How much money did it take to get him to betray the most basic ethical principles of his profession as a physician? Remember the Hippocratic Oath, do no harm? He knows he can’t experiment on me like this. It violates my autonomy, my right and only mine to decide what’s best for me. Does he really believe he’s helping people? Has he forgotten the Nazis and all the research abuses that occurred in our own country after World War II? You can’t do things like inject live cancer cells in elderly, diminished capacity patients to see if their immune system fights back. This is the 21st century. Clyde, I understand, probably a mix of greed and professional pride. I suppose I can only hope the others they subjected to this experiment were really unconscious, unaware of what was happening. What will this drug do to me? Who's that coming into my room? Why are they returning?

"Watson, I don't want you to leave here tonight thinking you're doing something wrong. I really believe Clyde presented me with a once in a life-time opportunity," Sherman says. "Not everyone agrees with this kind of aggressive clinical research, but if we're going to make progress, we have to take chances. The benefits for society clearly outweigh the risks for your brother. He is going to die. There's nothing we can do about that. Why shouldn't his death help others? As far as I'm concerned it would be unethical not to use him to test this drug. Remember, though, you must not tell anyone about this."

"When do I get my $10,000?" Watson asks. "Age has some privileges, but not many. I haven't had a job in 10 years. My wife's in a nursing home. She doesn't even recognize me. Mellman let me work at the grocery store as long as I could still stuff bags and help the old ladies. My back finally gave out. Believe or not I used to be 6-4. Now I'm all hunched over."

"You'll get your money as soon as the ethics consult is over," Sherman says. "Clyde will wire it to your bank account."

"What account?" Watson says. "I want cash."

How could my brother be so venal? I wish I could reach out and shake him by the collar. It's odd but I actually worry he doesn't realize he's breaking the law? I don't know what happened to him at college, our parents never talked about it. When he graduated he was drafted, but he only served a few months. Dad said he had a nervous breakdown just before he was about to be sent overseas to the war. The Army sent him home with an honorable discharge, but it must have been humiliating for him. Everyone in the neighborhood knew he failed, but no one ever talked about it. Watson spent the rest of his life as a bag boy at Mellman's grocery store; what a waste. I never knew who to blame; Watson, our parents or the Army. I didn't spend much time worrying, though. I went on with my life. Maybe that was wrong. I could have tried to talk to Watson; find out what happened.

Who's this coming in my room? It must be getting late. That's Morgan's voice. Maybe she overheard what Sherman was saying.

"What do you suppose Sherman and Watson were doing?"

"I don't know," Peabody says. "It's unusual for Sherman to be here at this hour. They didn't have much to say to us as they left."

"Thanks for coming in tonight," Morgan says. "I wanted to talk to you about a couple of things. The first is the ethics consult tomorrow afternoon."

"Did you get yourself assigned?" Peabody asks.

"Yes. Will you be there?"

"Of course, this is as much my case as Sherman's."

"Have you made up your mind like Sherman?" Morgan asks.

"I don't see any reason to continue treating him, if that's what you mean," Peabody says. "It's clearly futile, and a waste of resources that could help someone else. It's not in his best interests, if you ask me, to keep him here tethered to all this equipment so he can die from an infection. That’s what will happen, and you know it. How many times have we seen this scenario play out? There’s nothing more we can do.”

“But isn’t it too early to tell if he can recover?” Morgan asks. “You said so yourself.”

“Yes, it’s often difficult to judge these cases. It can take time and more testing to make sure the patient is not likely to recover consciousness, but this hospital doesn’t have the resources to wait. I heard from another physician, a friend of mine at a hospital outside the city, that her patient died waiting for transfer to this ICU. What are we to do? Anyway, Sherman’s in charge and Mr., I mean Dr. Force’s brother is the decision maker. It’s their responsibility and I can’t say I don’t agree. All the medical data suggest he won’t recover. He can’t stay here indefinitely.”

“Please do me one favor,” Morgan says. “The ethics consult should be held in this room. The people who are deciding to let this man die should be looking at him as they discuss his fate. Will you back me up?”

“Sherman won’t like it,” Peabody says. “Once he makes up his mind, he wants everything over with cleanly and quickly, with a minimum of fuss; holding the consult with your Dr. Force present might create a problem for the community members of the committee.”

“Deciding something like this should be a problem,” Morgan replies.

“I’ll see that everyone gets to Dr. Force’s room.”

“Thank you, just one more thing.”

“Now what?”

“You recall my parallel charting project?”

"Yes."

"Will you try it?"

"I don't know. I don't have the time."

"Come on. We can do it together. Wilbur deserves more than your medical smarts. He deserves some compassion. Isn't that what you're always telling the residents? 'We are Compassionate Care?'"

"All right," Peabody agrees.

"Good, we'll start tonight."

"Oh no, you don't. It's too late."

"There's a note pad at the nurses' station. Get a pen and spend the next half-hour, hour at the most, writing down your thoughts about Wilbur Force, the man, not the stroke victim. I'll sit in here and write out my thoughts."

I should not have a hard time staying awake. I keep obsessing over the drug they're planning to shoot in me. Isn't anybody watching these people? Sherman is using me against my will. Maybe he really has convinced himself it makes sense. It can't be all greed. Oh yes it can. What am I thinking? I'm not giving him any break. Never underestimate the power of greed. Here's Peabody again.

"Winston let's hear it," Morgan says.

"This is different, so bear with me," he says.

In the ICU we tend to think of patients more as disease states, than people. They aren't like the people you work with or know on the outside. Most are unconscious when they arrive and remain in that condition. Many die. It's hard to connect emotionally to a person lying motionless, hooked up to an array of medical equipment, their bodily fluids *excreted through tubes into stench-filled containers. The smell stays with you after you leave their rooms and it's a little different for each one. I can tell when someone is dying. The smell is thick and hangs in the air.*

Families can be annoying. 'I want everything done,' they say. They don't understand. 'I'm waiting for a miracle,' they plead. Don't they know miracles can't be summoned? I overheard a nurse tell a patient's daughter when life support is withdrawn, if a miracle occurs, it will happen then. The miracle may actually be death.

This is a death ward. It's an intensive death unit. We try our best to save them, but by the time we get them they're mostly gone, or surely will never be the same. Many times we feel helpless. They have suffered that black swan event, a catastrophe that neither they nor their families understand. All they know is nothing will ever be the same.

'I was telling my wife a joke at breakfast,' an elderly man said. 'She started mumbling, spit rolled down her chin and she collapsed. Now what?'

I don't have many good answers. Most times the families aren't listening anyway. I can't promise miracles. I'm a scientist.

I don't fault the patients. The fat man who smoked; should I worry less for him than the pious woman who attended to her health and spent her life caring for others?

Wilbur Force is not unlike many patients I see. I don't know much about his life. I know much more about his death. We hold the moment in our hands. Are we killing him? If he could tell us he wants to die and we let him, are we assisting his suicide?

Tomorrow Wilbur Force will have his hearing, one he's not privy to and one that already has been decided.

"That's pretty deep for a first attempt," Morgan says. "Do you feel any different?"

"I suppose. Writing out these feelings makes them more real," he says. "But I'm not so sure I want to continue doing this. It's easier to handle medicine without emotion."

"Do you want to hear my entry," Morgan says.

"Not really," Peabody says. "I've had enough drama for one evening."

"That's okay. I don't think this will be one I'll share with anyone, except Wilbur," she says. "I want to read it to him."

"He can't hear you, Morgan. Good night."

Tomorrow's a big day. If you could just give me a sign, but I know you can't. I trust Winston. If he says you can't recover, I guess you can't. I've seen miracles happen in this hospital, and I'll continue to pray for you.

The sight of you stirred something in me. I think it's a feeling of what might have been; if my life had been different. I don't mean with you, I mean just different. I'm going to make them keep your eyelids open tomorrow. It makes you look more real. It's easier to dismiss someone whose eyes are closed. It's like you can't see them because they can't see you. This is sounding foolish. I must be tired. Good night.

Good night Morgan. I keep trying to give you a sign, but nothing works. Today I thought I moved a finger. I was sure of it. I felt it. Then a woman came in scolding someone not to touch me; most likely a child who lost his way.

Tomorrow is bigger than Morgan knows. Once my death sentence is read, the experiment will follow. I can't believe it. What about the women who overhead Sherman's plans? They can't keep quiet. They can't sit back and let Sherman abuse me. I'm getting agitated again. I'll try to sleep.

Exhaustion

Not much sleep for me. It’s after dawn based on the bright light coming in the window. That younger nurse who overheard Sherman’s plans to experiment on me is in my room. She’s looking in my eyes, asking if I hear her. She actually asks how I’m doing. Maybe I shouldn’t expect much from her. Here’s the older nurse.

“Let’s give him a sponge bath, change his sheets and clean up the room later this morning,” the older woman says. “They’re going to hold the ethics consultation in here this afternoon. It’s the chaplain’s idea; some touchy feely bunk about looking at the guy while you discuss whether to pull the plug.”

The younger woman interrupts sounding excited, and says a nurse yesterday saw Sherman, a man in a business suit and the patient’s brother in the room.

“You know what that means, don’t know?” she says. “I’ll bet the guy in the business suit is from a pharmaceutical company. They are plotting to use this patient for their drug test. We have to say something.”

“Not if you want to work at this hospital,” the older one says. “I told you, Sherman’s been here a long time and he’s too powerful.”

“But I did some digging,” the younger nurse says, “and found out from some nurses in the medical and surgical ICUs that Sherman’s been doing this for a while.”

“I don’t care,” the older nurse says. “I’m sure Sherman only uses patients who were gonna die anyway. Just leave it alone.”

“How can you say that? What if it were your relative? Who do you suppose Sherman’s working with?” the younger woman says. “I’ll bet he’s not administering the drug himself. He wouldn’t dare risk getting caught.”

“Maybe it’s Peabody,” the older one says. “It sounded like he was willing to troll for patients. He doesn’t fool me with his do-gooder act. He’s just as ambitious as all the docs. If there’s money in it, you can bet he’s in. He has to genuflect to Sherman for the next step in his career and pay off all those medical school bills. The richer they are, the greedier they are. That’s just the way it is.”

“Quiet,” the younger one says. “Winston is coming. It must be time for morning rounds.”

As the women exit, I hear the voices of the medical team gathering at my door. Sure enough, there is Sherman’s booming voice. The crowd moves in with Sherman and Peabody on either side of my bed.

“Any change in Mr. Force?” Sherman asks.

“No, all his vital signs are stable,” Peabody says.

“Mr. Force, Mr. Force, can you hear me?” Sherman shouts. “Can you move your eyes? Blink once if you can hear me. There’s nothing. Keep hydrating his eyes and keep the eyelids closed. I want them closed when we have the ethics consult this afternoon.”

“Who’s participating? Peabody asks.

“You, me, that chaplain Morgan, Kopeckne, and two other members of the ethics Committee, Markeisha Sullivan and Adel Smith-Foster. They’re community members of the committee,” Sherman says. “That gives us the required six. I’m a little worried about Markeishia. She’s an activist. You know the type, always looking for a fight.”

“What’s the likely outcome of the consult?” asks a first year resident.

“Withdrawal of life support,” Sherman says. “The patient’s brother is acting as surrogate and said he wouldn’t want to live in a comatose state.”

"What do we know about the patient's life?" the resident persists.

"Enough," Sherman says. "Now let's get on to the next one. What room number?"

"L810," Peabody calls out as he leads the group from my room.

My eyes are closed and the room is quiet, except for the incessant thump of the ventilator and the noise of monitors. I feel a collapse in my chest like the emptiness of deep sadness. It doesn't take long for fear to follow and for my thoughts to start running, revving up slowly in a kind of muted panic, then jumping wildly around in time, peppered with shouts of *'save me'* that no one hears. Where are they coming from? My mind is like some exploding star, shooting solar flares in all directions.

Pride in a fourth-grade poem
Pain from a wounded knee
Satisfaction in earning a Ph.D.
Remorse from a foolish adultery
Happiness of a warm embrace
Shame in driving drunk
Hope for what's yet to be

The pace of memories suddenly slows leaving raw emotions with no pictures, no associated memories, all of them foreboding.

Loneliness
Frustration
Fear

It has to be the realization, once and for all, that I'm never getting out. It's as if I'm experiencing two lines of thought; one trying to follow the dialogue and action around me and the other wrestling with my memories and the helplessness of my condition.

I’m terrified of dying, but what’s the alternative? And the thought of being an experiment for Sherman makes me want to reach out and strangle the SOB every time he looks in my eyes. How many people get to see their killer up close and watch their death cruelly unfold like a stage play? My life was not exemplary by any stretch, but what did I do to deserve this damned fate? Nothing of course; it’s all just chance and I know it, but there should be something more. I should be able to fight back. These periodic paroxysms I experience are debilitating. I’ve lost track of time again. I’m slipping…slipping…

Disbelief

What are all these voices? It’s Sherman. I can’t see anyone.

“Folks, please move inside the room. At the request of Mrs. Chu, the chaplain on the ethics committee, we are holding this consult in the patient’s room. I hope everyone was able to review the background on this patient.

“I see everyone is nodding in the affirmative. Let’s go then. This is Wilbur Force, 77 years old. He suffered a severe stroke that has left him in a comatose, unresponsive state. He is completely paralyzed. The other doctors have seen the findings of the EEG and two CT scans and they agree Mr. Force is unlikely to recover any level of movement or consciousness. The patient has no advance directive. His brother was found and agreed to serve as decision maker, which as you know is permissible under state law. The brother, Watson Force, stated the patient would not want to live in this condition. He agrees with the medical team that all life sustaining treatment should be withdrawn so the patient is allowed to die peacefully. Are there any questions?"

"This is pretty serious stuff, isn't it," a female voice says. "I've read the material you gave us and I'm familiar with the patient's condition, but I've never been part of something like this."

"This is part of the hospital's new policy," Sherman says. "We wanted to include more non-physicians from the ethics committee on these cases to get different perspectives. There are difficult issues involved here. The brother's decision would be enough to withdraw treatment. But I wanted to go the extra mile. As an ethics committee, we have to consider the best interests of the patient. Do you recall from our retreat last fall? Weigh the benefits of prolonging this patient's life, with no hope of recovery, against the burdens that places on him. He has no awareness, no social interaction, no quality of life and eventually he'll die of some sort of infection. It's not fair to him. Of course, there's also the justice issue. How does the hospital allocate limited resources? This patient is not going to recover. We need to think about the patients who will."

"How do you know he won't recover?" another female voice says.

"That's a good question, Markeisha," Morgan responds. "Dr. Sherman, how can you and the others be so sure after less than two weeks?"

"Dr. Peabody, do you have the CT scans?"

"Yes," he says. "If you look on this monitor you will see the CT scan taken several days after the patient arrived in the ICU. You can see the damage to the lower part of his brain here; and there is no indication of neuronal activity in the upper portions where consciousness is located. Given the other symptoms of paralysis, lack of any response to verbal commands, and no hint of communication from him, we conclude he is in an irreversible coma."

"What's that?" another female voice asks.

I could feel my right eyelid sliding up.

"Is he opening his eyes?"

"No, Adel," Peabody says. "We have his eyelids closed and his eyes hydrated to keep them from drying out. One of the lids is slipping up."

"I want to open his eyelids," Morgan says emphatically. "The consult committee should see what he looked like when he came in here."

Without hearing anything from anyone, my eyelids are opened. I see Peabody. I try furiously to move my eyes. I hear short gasps from one or two women.

"Dr. Peabody, show the committee the scan we took over the weekend," Sherman proceeds.

"This scan was taken last Saturday more than a week after the first one," Peabody says. "The important point is that there is no change in brain activity."

"Which means, the patient is not going to recover, based on our experience," another male states confidently. "We would expect to see some positive change if he had a chance."

"Thank you, Dr. Kopeckne," Sherman says.

"The science is clear," Kopeckne continues. "The patient likely could live on the ventilator and with the feeding tube and with round-the-clock care for an extended time. But he won't recover. His body will continue to waste away, and if his heart doesn't give out, he eventually will die of an infection."

“How can you be so sure? Morgan asks.

“We’re as sure as the science can be,” Sherman says.

“Don’t forget the justice issue,” Kopeckne interjects. “We can’t keep him in the ICU. It’s far too expensive. We can’t put him in a step-down unit indefinitely, and he needs too much attention to send to a regular room in the hospital. There’s nowhere for him to go.”

“So all three doctors say this patient will not recover,” one of the new female voices says. “We haven’t heard from Dr. Peabody.”

I see him with my peripheral vision on my left side. His head is down. He pauses as if maybe he will counter his colleagues; wishful thinking on my part.

“Adel, I agree with Dr. Kopeckne. The second scan confirms the patient is unchanged. We would have expected some sign of improvement, even slight indications of less damage to the brain stem if he had a chance. He has not responded to anything at all since he arrived in the emergency room.”

“Are there any other comments or questions,” Sherman says. “Are we ready to vote?”

“Morgan, what do you think?” another female voice asks.

“I believe what the doctors are telling us,” Morgan says. “I’ve visited this patient almost every day, talking to him and praying for some sort of sign that he might recover. But I haven’t seen anything.”

“This is such a big step,” the woman says. “Why isn’t his brother here?”

“Once the family makes a decision like this,” Sherman says, “there’s no need to subject the loved ones to our clinical discussions.”

"But that's a good point," Morgan says with a slight tremor in her voice. "We haven't talked at all about who he is. Before we decide to let him die, we should all know something more about him."

"You have all the information we received from his brother in the background materials we gave you," Sherman says.

"I know him," Morgan blurts out.

"You do?" Sherman asks. "Why haven't you said this before?"

"What difference would it make?"

"Well, not much I suppose," Sherman says.

"It's been a long time since I knew him," Morgan says slowly. "I was a student of his in college. I lost track of him after I graduated."

"Okay, sweetie," says one of the female voices. "I think there's something else going on. Tell us about him. We should know more than these pictures of his brain and the scant information provided by his brother, who admits he hasn't talked with him for 30 years."

"I suppose there's really not a whole lot for me to say either," Morgan says. "But I felt I wanted to say something. Mr., that is Dr. Force, was a philosophy professor who taught ethics. He has a Ph.D., not a medical degree, but he focused on medical ethics. He was ahead of his time, if you ask me. Forty years ago the medical profession was still very paternalistic. The concept of patient autonomy was just beginning to develop. Wilbur, er Dr. Force, believed patients had a right to know the full extent of their condition so they could make their own informed decisions about their treatment. I think that's why I've been so involved in his case. He's just so helpless."

“What else?” asks the female voice.

“Well, he had a wife,” Morgan says. “But I didn’t know her. I didn’t know he had a brother, but from what I’ve seen, I’m not so sure the brother should be making decisions for Dr. Force.”

“And what else?” another female voice asks. “There’s got to be something else going on between you and him for you to be so involved.”

“He cared deeply about his students,” Morgan says. “As soon as I saw him in the ICU, I recognized him. I hadn’t thought about him in years. Knowing what he taught us, I wonder what he would think about our discussions on ending his life. I think he would suggest caution and advocate for more time to be sure.”

“That’s neither here nor there,” Sherman says. “The facts are simple. This patient will not recover and he has nowhere to go. His brother, who is the legal decision maker, has said unequivocally that Dr. Force would not want to live under these conditions and has authorized us to withdraw life sustaining treatment. Are we ready to vote?

“Kopeckne?”

“Withdraw life support. It’s the humane thing to do,” Kopeckne says. “No one would want to live this way. It’s definitely in his best interests.”

“Dr. Peabody?” Sherman continued.

“Withdraw,” he says without hesitation.

“Adel, are you taking notes on this?” Sherman asks.

“I am,” she says. “The ethics committee asked me to record the discussion and the vote for the case file. And I vote to withdraw.”

“Markeisha?” Sherman asks.

“I really don’t know what to say,” she answered. “If he were my relative I’d want to wait a little longer. How do we know if God wants him to die? God makes those decisions, not us.”

“Markeisha, we can’t wait for miracles indefinitely,” Sherman says. “Isn’t that right, Morgan?”

“Markeisha?” Sherman says impatiently.

“I’m not voting,” she says. “I don’t like this. I’m uncomfortable.”

“Morgan?” Sherman says.

“I’m abstaining with Markeisha.”

“Adel, please make sure to record Markeish and Morgan’s abstentions,” Sherman says. “The vote to withdraw treatment from Dr. Force is 4-0 with 2 abstentions. Dr. Peabody, make the appropriate preparations and get the paperwork in order. Withdrawal will occur Sunday morning.”

“Why wait four days?” one of the women asks.

“It’s hospital policy,” Sherman says. “We have to give the legal staff time to review the patient’s medical history, the brother’s signed decision to withdraw and other paperwork from the ethics committee, including the record of this consult and the votes. Everything has to be in order. That’s it people. Thank you for your time. I know everyone is busy.”

Everyone leaves except for Peabody and Morgan. I don’t know what to think. My world, what there is of it, is again ripped apart; collapsing on the street, awakening to find myself entombed, and now they want to finish me off. Who do these people think they are, judging my life in such a way? Was I this callous? I think I was more sensitive. I hope I was. I hope I would have recognized someone in my condition. They have no idea what they're doing. If only I could wriggle free from my skeletal prison.

What's this now? Morgan is caressing my hair as she talks with Peabody. What's she saying?

"Winston, I'm going to write about this in my parallel chart. I want to try to sort it out. I suggest you do the same. You looked uncomfortable to me. I have a service this evening at my church. I'll be back tomorrow morning. I'll share my thoughts with you after rounds if you want. See you tomorrow."

"Bye," Peabody says.

He remains in the room after Morgan departs. He looks at the various monitors and the lines connecting me to them. I feel the tubes moving back and forth as if he is checking to make sure they are secure. This is the night Sherman means to experiment on me. Is Peabody his conspirator? I hear him leave. I dare not drift off, but I tire so easily.

Who's that? It sounds like Sherman. It is. Who's he talking to? I must have drifted off, despite my best efforts to stay awake. It's barely light in my room. It reminds me of watching the gloaming over the city from my balcony. I wish I were there. How long was I asleep? Is it Peabody? It is. He's the collaborator.

"Close his eyelids," Sherman says. "It bothers me."

"I don't like this," Peabody says.

That's good. That's good, Peabody. You know this is wrong.

"What's the problem now," Sherman says. "I thought you understood what's at stake."

“It’s unethical and illegal,” Peabody says. “You’re circumventing the whole clinical trial regulatory process, not to mention the ethical guidelines of human subjects’ research. You need an investigational new drug approval from the FDA and then you need approval from the IRB. Neither would allow something like this. You cannot give an experimental drug to an incapacitated patient who has no chance of benefitting from it. The fact the patient is going to die anyway is no justification, and you know it.”

“Winston, remember the big picture,” Sherman says. “This is an opportunity for the hospital to advance the science of treating brain trauma in stroke patients. It’s huge. It will establish this medical center as a world leader in stroke research. Plus, I’ve been guaranteed that whatever company develops the drug, it will use this hospital as the lead institution. The result will be a long-term, lucrative relationship for all of us.”

“What company is going to take data from an illegal trial to develop a drug?” Peabody asks.

“You would be surprised, I’m sure,” Sherman says. “My associate already has an offer from a company, provided we can get the data in the next several weeks. The company’s tired of waiting. That’s why this patient is so important. We don’t know when we’ll have another patient that fits the profile. It’s too risky to deal with patients who have family or friends.”

“I don’t like it,” Peabody says.

“You liked the extra cash I gave you to identify trial subjects,” Sherman says. “You want to return the money? There’s more, much more, if this is successful. This patient is the last subject, I’m sure of it. If we can show the liver toxicity is negligible and the brain tissue improvement significant, the company is ready to move immediately into development.

“Think of it. Forget the money. Can you imagine having a drug that reverses brain damage? How many people could we have rescued with such an advance? Think of all the people we watched die because we couldn’t do anything for them.”

“What’s the name of the company?” Peabody says.

“It’s none of your business. All you need to know right now is that if you help us, you’ll have a nice fat check waiting for you next week,” Sherman says. “Plus, you can be sure of a good recommendation from me for your next career move. Now, here is the vial with the drug. Don’t give it to him until the overnight shift comes on. After you deliver the injection, watch for the spike in his heart rate. We don’t want to alarm the nurses. The heart rate should return to normal quickly. Then you can leave. You’re done.”

“Why do want me to do it?” Peabody asks. “I haven’t administered the drug to any of the other patients.”

“Morgan’s a little too close to this one,” Sherman says. “And some of the nurses are whispering. The head nurse is a friend of mine and she has kept her charges in line, so far. She believes in what we’re doing. But if Morgan thinks I’m messing with her long lost love, she could make trouble. I figured you can take care of her. I’ll expect a report in the morning just before rounds.”

Sherman departs, leaving Peabody at my bedside. Sherman has twisted everyone’s morality upside down with his promises of cures and money. Will this nightmare never end? Peabody departs. There’s nothing to do but wait, and relax. It’s so hard to fathom. I am helpless.

Even at the lowest point in my career I still had choices. I was being considered for the chair of the philosophy department at University of Pennsylvania. I was only 40, but then the DUI. Daria warned me not to drive. I didn't have much to drink; some champagne at a faculty get together to honor a colleague. 'I'll come get you,' she said when I called to say I'd be late. Don't bother, I told her. The arrest ended my chances for Penn. I stayed at Westminster and attended to my students, and my work at the hospital. I had choices. What do I have now?

Relief

"Morgan what are you doing here?" Peabody asks. "It's after midnight."

I didn't know she was here. Morgan must have slipped in quietly.

"I'm praying for him," Morgan says. "I wrote my parallel chart on the ethics consult and I wanted to read it to him. I know, I know, he can't hear me. What are you doing here?"

"I did some parallel charting of my own," he says. "I'm glad you're here. I was beginning to wilt under the pressure."

"What pressure?" she asks.

"Sherman's…listen you can't tell anyone about this, at least for now. I'm not sure what to do, but I had to get my thoughts straightened out. Here it is. Read it later and we can discuss it. Go ahead with yours. I thought the consult was straight forward. We followed policy. What did you feel?"

Morgan speaks in a quiet voice just above a whisper.

"It's not long," she says.

Despite all our policies, I feel there is something wrong with making these kinds of life and death decisions. Who is qualified to sit in judgment of this man's condition, of his life? What do we really know about his physical condition? The machines are not fool proof. Maybe it's time for Dr. Force to go. I don't know. None of us, not even the doctors can know for sure. Have we done all we can do? What gives us the right to decide his fate?

Let's not pretend we're doing this for him. Let's not wrap our best interests in a shroud of what's best for the patient. He's an economic burden, an inconvenience. It's all too secretive for me.

"I'm not sure what to say," Peabody remarks.

"I want us to recognize what it is we're doing," Morgan says. "We don't know what Wilbur would want. I don't believe his brother qualifies as a legitimate surrogate decision maker. I don't believe in surrogate decision making. Wilbur is a victim of a society that can't afford him. Before the consult I saw Adel and Markeisha pulling on his toes. What are we doing?"

"Let's go," Peabody says. "There's a lot more going on here than you know. It's shocking, really, and I almost let myself be deluded. You'll see when you read my parallel chart. But please, don't share it with anyone until I tell you. And please don't judge me too harshly."

I don't know what to think. If it wasn't for this damn ventilator I'd muster every ounce of energy I had to exhale an explosion of elation with my inner gases that would rival a whale's spout. Peabody, at least for now, came to his senses. He's not going to give me the experimental drug. Hopefully it's more than a temporary reprieve. My life is measured in hours now, about 96 by my reckoning, but I won't spend them as a guinea pig. I'd love to hear Peabody's reasoning, the thought process that strengthened his resolve to challenge Sherman.

Maybe Peabody's having second thoughts about killing me. I don't want to think about that now.

Morgan's insights into my fate were surprising, a bit of irony if you think about it. She's questioning the ethical status quo. Whose best interests are being served? How coincidental, my sacrifice aligns with my best interests. Let me know if there's anything else I can do.

I am a hard case for this hospital, I get that. But at least if I were in a coma or a vegetative state, presumably I wouldn't know what was happening. How am I different from an unconscious patient? Do I get to live because I can think? Since everyone decided I'm not conscious, I'm in a unique position of thinking through, from their perspective, whether patients in irreversible comas have a life. They can't communicate, but neither can I.

I hear someone in the room. I guess it's the overnight nurse. It's time for another shot of something. I feel it entering my arm, but I'm panicking. That shouldn't happen. Did Sherman recruit another conspirator after all? I think I'm all right…I'm feeling sleepy….

Anticipation

What's that? It sounds like something metal crashing into the door of my room, but I can't be sure. It looks like morning. My eyelids must have rolled up during the night. I see the sunlight. Now I hear a lot of commotion outside my room. Here's Peabody standing next to me with a nurse. The others are outside mumbling.

"You ducked in here for cover too, eh? What do you think that was all about," says the nurse.

"I'm sure I wouldn't know," Peabody answers.

In comes another person chuckling.

"What happened? The nurse asks again.

"Dr. Sherman just threw a fit," the woman says. "I missed it by a minute. One of the other residents saw him talking with you," she says, gesturing toward Peabody. "Then he tried to get into the computer, but forgot his password. A nurse reminded him it was Aida. That sent him into a rage and he kicked the mobile computer cart across the floor crashing it into this doorway. I must be the only one who doesn't know Sherman's third wife is an opera singer and ran off with her coach. Aida is her favorite. I met Dr. Sherman last week in preparation for starting my residency this morning. What an introduction. Carmen Alvirez is my name.

"I'm Winston Peabody."

"Oh good," Alvirez says. "Dr. Sherman told me to report to you."

"And I'm Martha. Don't let Sherman scare you. He's wound pretty tight. He's been here a long time."

"I know," Alvirez says. "That's why I applied here. He's considered one of the best neurologists in the nation. He spoke at my school last spring. I was very impressed, so I checked him out.

"Where is he now?" Peabody asks.

"He's gone," Alvirez says. "Stomped off, shouting he'd be back Monday."

"Let's go introduce you to the others," Peabody says. "We still have rounds to complete."

Sherman's tantrum has nothing to do with his runaway wife. Peabody told him he didn't give me the drug. And that also means I received something else before falling asleep. That's comforting even after the fact. Now Sherman will have to tell his pharmaceutical partner in crime they'll have to find another unsuspecting test subject. Maybe Peabody will follow through on his attack of conscience and report Sherman to the ethics committee or better yet, the police.

Rounds have started. Here comes the gang. I'm in relatively good spirits for a condemned man. Maybe it's knowing that once I'm dead my head won't be split open to fulfill Sherman's avarice. Until now I never understood what role bodily motion played in the manifestations of emotions; whistling as part of happiness, crying with sadness, pounding your fist in frustration, jumping for joy. It's as if I can't fully understand my own mental state because I can't move.

"For the benefit of our new colleague, let's go over Dr. Force's condition," Peabody says.

There's an attractive young woman standing over me gazing into my eyes as Peabody recounts my brief, but distressing medical history as a temporary guest in L802 of the Compassionate Care neuro-ICU. She must be the new resident.

She pulls back as if startled when Peabody reminds the group I am "to be allowed to die," as he terms it, during the weekend. I thought I had until Sunday. Now he's suggesting the end of me could come earlier. How can I prepare if I don't know when the end is coming?

"I don't understand," Alvirez says. "This patient hasn't been here long enough to determine if he will or will not recover some level of consciousness. I have some experience with these conditions."

"Dr. Sherman is among the most competent neurologists in the nation, Dr. Alvirez. You said so yourself. He has thoroughly examined the clinical data and determined in his expert opinion that this patient is in an irreversible coma. I suppose you can never be 100 percent sure, but if Dr. Sherman says it's unlikely, that's enough for this hospital. We have the assurance of the brother this patient would not want to exist in his present condition."

"Yes, but I saw a case that looked like this when I was in medical school," Alvirez says. "It's called locked-in syndrome or pseudocoma. It's rare and difficult to diagnose, especially if you're not looking. It can take months. The person appears to be comatose but is actually conscious in a completely paralyzed body. Usually the patient can communicate with eye movements and blinking, but there are cases of complete inability to move, even the eyes."

"We don't have that kind of time," Peabody says. "The ethics consult was held yesterday. We followed procedure. The vote was in favor of withdrawing care. Even though we have the brother's permission, we took the extra precaution of conducting the consult."

"You have to look for activity specifically in the amygdala. If the patient is conscious the brain scans should reveal some activity there based on the fear and anxiety anyone in that condition would be experiencing," Alvirez says. "Can you imagine how terrifying it would be to be lying here listening to this conversation?"

"All you're doing is speculating," Peabody says. "Dr. Force hasn't communicated in any way for the 14 days he's been in this bed. He's been completely motionless. His brain scans have shown no significant activity. If he were conscious we should see something. To look for activity in the amygdala we would have to take him off all medications and do another scan, probably with an MRI or PET scan. Medicare won't pay for that. The hospital isn't going to pay for it unless Sherman authorizes it. He isn't here, and he wouldn't if he were. Now let's move on to the next patient."

Strange, I'm not as agitated as I expected over Winston's refusal to entertain the new resident's suspicions. Have I accepted my fate? Are the medications holding back my anxiety? I don't think so. I believe I'm thinking rationally. I'm upset, of course, but I don't think I'm depressed. I don't feel desperate. I'm not in any pain at this point. I can't imagine months or years in this condition, particularly if no one ever realizes I'm here. Being warehoused in a nursing home until infection, neglect, or abuse kill me is as disturbing as my current state. Loneliness is also a worry. How could I cope for an extended time, cut off from others? My one-sided conversations are useless.

I may have not been the greatest professor or writer with the best insights. I was more a synthesizer than original thinker. I had aspirations of greatness. Who doesn't? Mine were tempered by weakness of character. The drunken driving arrest relegated me to damaged goods. Thereafter I accepted my role as, at best, a second teamer. Still I loved people, my students, colleagues and friends. I was just beginning to get my bearings in this lovely Southern city by the sea, starting over, engaging a few acquaintances in preparation for revealing more of myself, moving beyond ‘hello, how are you?’

It’s just as well they kill me. I can’t bear to be left alone. I enjoyed it for a time after Daria died, alone with my thoughts, writings and musings. But I soon craved conversation and friends. It seemed silly to sit alone with my memories, or as James Thurber wrote “a pocket full of old used years.”

But what if I could communicate? Even if I could, I’m unable to care for myself. I’ve become asocial. I suppose some may question my humanity. My physicality has become mechanical. I breathe and eat by machine. Catheters and tubes drain the wastes. Medicines keep my heart beating in just the right rhythm. There are someone else hands to wash me and change my linens. If they could suspend me in a tank, filling it occasionally with clean water to cleanse my skin, there would be no need for anyone to concern themselves with me. How much would it cost? Some square footage, electricity and water. I won’t last too long.

“Dr. Force, are you in there?”

It’s Alvirez. Rounds must be over. She’s back for another try.

“Who are you?”

It’s Morgan.

“I’m Carmen Alvirez, a first year resident.”

“I’m sorry. I really am, but you’re wasting your time. Dr. Force is comatose, and he can’t hear you.”

“Who are you?”

“I’m the chaplain, Morgan Chu. I know him and I’ve been praying for him since he arrived about a week and a half ago. He was my ethics professor in college. I have not seen him for years.”

“I’m concerned that our patient may be locked-in, and we haven’t had enough time to evaluate him,” Alvirez says. “Of course, I’m just a first year resident. But I’ve read the research studies on this condition. With proper support and even a limited amount of socialization, a locked-in patient can experience a positive quality of life.”

“Have you told Dr. Peabody?” Morgan says.

“Yes, this morning at rounds, but he wouldn’t listen to me. He said Sherman is the attending and the decision has been made to terminate life support this weekend.”

“Dr. Peabody has a lot on his mind,” Morgan says. “I’ll talk to him.”

“My first day hasn’t exactly gone as I expected. First Dr. Sherman has a melt down and stomps off, and then the first patient I encounter seems to be getting less care than I would have thought,” Alvirez says. “This is one of the best hospitals in the nation.”

“Welcome to Compassionate Care,” Morgan says, “or the House of Poor, as we call it. Dr. Force actually has some health insurance. Most patients have nothing except maybe state Medicaid insurance, which pays very little.”

“What does that have to do with anything?” Alvirez asks

“You’re kidding, right?” Morgan replies “You should have a heart-to-heart with Dr. Peabody about this place.”

Alvirez stands over me, periodically looking in my eyes. She is young, maybe late 20s, and quite stunning. She has smooth skin, nearly perfectly proportioned features; a brunette with dark brown eyes. She is trim and fit. I can tell by her small wrists and taut forearms. I wish I could see more of her. If she would only smile, it would complete my portrait of her. I may not see her again.

“I have to go,” she says, “a bunch of hospital orientation sessions to sit through.”

“I’ll tell Dr. Peabody to talk with you, although I doubt I’ll need to,” Morgan says.

Alvirez leaves and Morgan stands next to me, silent, for several moments, then pulls out papers from her smock. The chaplains wear a colorful coat over their street clothes. The colors remind me of those you see in churches’ stained glass windows.

“I’m going to read something to you, Wilbur,” she says. “It’s terribly disturbing. I shook with anger when I read it. It’s from Winston. I know you can’t hear me. But somehow maybe some of what I’m saying is getting through. I want to think so, anyway. And it’s important for me to tell you I had nothing to do with this. Winston did the right thing. I’m proud of him for that. This is one of the parallel chart entries I encouraged him write, to get him to understand his feelings about his patients and their medical care. It’s much more than that. It’s a confession.”

I fear just writing out these thoughts puts an end to my career. I can’t believe I came so close to allowing selfishness to push aside duty to my patients. I can’t blame Sherman entirely. I almost went along with him. Some aspects seemed reasonable, although I knew it wasn’t right. It was like watching myself tumble off a bridge.

I know Sherman is likely burned out from the countless tortured lives he’s tended to in room after room of the ICU. I think he convinced himself he is helping people. He used to be a good doctor.

He wasn't alone. He had accomplices. I know of at least two; Kopeckne and Horatio Clyde, a scientist with what he thinks is a potentially life-saving drug. Sherman conspired with them to secretly test the drug on stroke patients in an irreversible coma or persistent vegetative state, with no family or friends to interfere. They needed safety data from 20 patients to prove to a pharmaceutical company the drug was worth the risk of developing. In the case of Dr. Wilbur Force in L802 of this hospital's neuro-ICU, his brother, Watson Force, presented a potential problem. He was paid off to go along with the peccant scheme.

Dr. Force was to be the final victim and I was to be the perpetrator. I couldn't do it.

Morgan sits down in a chair at the foot of my bed. I don't hear anything from her for the rest of the afternoon. She sits motionless through the broadcasts of two code blues in the rooms on either side of me.

"Morgan, what are you doing?"

"I'm not sure, Winston. I read your confession and then seemed to collapse in this chair. How many other patients in this hospital did you recruit for Sherman? Who were they? We have to tell the Ethics Committee their names."

"I don't know all the victims. The only one I was involved with is Dr. Force. I passed along names of comatose patients without surrogate decision-makers to Sherman over the past two years. He told me it was for some drug trial. I just assumed he was following the proper procedures. I didn't give it another thought, really. I was not aware of the previous experiments. They recruited me this time so as to not alert you to anything unusual."

“You shouldn’t leave,” Morgan says. “You put an end to this sordidness.”

“I’m not sure it’s over yet,” he says. “We still have the consult’s decision to carry out on Dr. Force this weekend. A new resident stirred things up this morning suggesting our patient may not be comatose. That was enough for some of the nurses to refuse to participate in Dr. Force’s demise, which means I’ll have to initiate it.”

“I think you should talk with Dr. Alvirez, especially considering how Sherman was planning to use Wilbur,” Morgan says.

“Alvirez? When did you meet her?”

“She was in here several hours ago trying to see if she could see any signs of awareness in Wilbur.”

“It won’t make any difference,” Peabody says. “The attorneys have signed off on the ethics consult’s decision. It’s too late to reverse. I’ll do it Saturday morning.”

“Talk to Dr. Alvirez,” Morgan says as they leave the room.

What a day. I feel like a yoyo. Up one moment and down the next. So it’s Saturday morning; all right then. I have another day to think through this and decide if I want to die or if I want to fight. It makes a difference. I want my final thoughts strong, not conflicted.

Not like the time in college when my girlfriend was pregnant. I wasn’t sure what do, and neither was she. I had just returned home for the summer. She was with her sister at the beach and she called to ask me to join her. I knew what she wanted. We talked before we left for summer break. We could get married, she said. We were in love. I didn’t think we should. We were too young. She ended the pregnancy. We were never the same. It ended our relationship. I don’t know what happened to her. I always thought I’d have children. The regrets in my life seem so numerous.

Uncertainty

I awaken this morning to someone, a nurse I suppose, putting more liquid or ointment on my eyes to keep them moist. Now he’s closing my eyelids and he’s putting something across them. It’s tape. In the past two days, my eyelids have refused to stay closed. They slip up halfway making me look even odder than normal. I don’t know, of course, but I imagine my body has morphed into something that looks inhuman. I feel I’ve lost considerable weight. The cheeks of my face feel like they’re concave, which I’m sure gives me an ugly gaunt look. It’s probably good I haven’t looked in a mirror. Not that there’s anything I can do about my looks, but I’m not dead yet, and I don’t want to scare Alvirez away. You never know, maybe she likes old guys. I used to be a pretty good flirt, or so Daria used to say.

“Thank you for agreeing to talk with me.”

It’s Alvirez, even her voice sounds sexy.

“Of course,” Peabody says.

“I’m concerned you’re moving too quickly with this patient.”

“I told you. There’s no way the hospital will let me postpone life support withdrawal for Dr. Force without Sherman’s approval.”

‘What about an appeal to the full Ethics Committee, or the hospital administration?” she argues.

“There’s no way the chair of the Ethics Committee will call an emergency meeting for one of Sherman’s patients unless he agrees. And the hospital administration will side with Sherman every time. He’s too valuable. He brings in too many paying customers. The brother has given his okay. The chief medical officer won’t even meet with us. He and the attorneys already have signed off. It’s a done deal. Dr. Force, or what’s left of him, dies tomorrow.”

“I know I’m new here. But listen to yourself,” Alvirez says. “This isn’t right. If there’s a chance you’ve overlooked something, you should make sure. Once he’s dead, you can’t bring him back.”

“You sound like the families of so many patients on this floor. ‘Do everything you can to bring back my husband, wife, daughter, son, uncle, aunt, or whomever,’” Peabody says.

“But the reality is we can’t help them. Even if Dr. Force were conscious, he’ll likely never recover from the paralysis. Where would he go? He requires too much care. There’s no telling how long he could live on life support. Essentially, we’d have to find someplace to warehouse him. Who’s going to pay for it? And how humane is it? It’s better for him, us, and society to let him die.”

“So what we’re talking about here has nothing to do with this patient,” Alvirez says. “For if he was conscious, it would be up to us to find a way to communicate with him, so he could tell us what he wants. What you’re saying is Dr. Force is something, not quite human any more, something we can’t deal with, and therefore it has to be discarded. Ever heard of the proverbial slippery slope? When does a person cease to be a person?”

“Oh so smart and pretty too,” Peabody says, gasping a bit. “I sincerely apologize. I didn’t mean that to sound the way it did.”

“Apology accepted.”

“I’m a doctor, not a philosopher nor a miracle worker,” Peabody continues. “My world is confined to the reality within these rooms on the eighth floor of this hospital. The fact is, Dr. Force, conscious or not, exists in a kind of limbo between life and death, and he’s much closer to the latter than the former, in my opinion. We can’t change what happened to him. We need to let him go.”

“What happens when you take him off the ventilator and he doesn’t stop breathing?” Alvirez asks.

“It won’t matter. We’ll take him off the medications keeping his heart stable. At most, he may live 24 hours. That’s not unusual. But he’ll die. We’ll give him medication for the pain. He shouldn’t feel anything.”

“Morgan told me you were different from Sherman, more sensitive,” Alvirez says.

“I don’t know about that,” Peabody says. “I’ll admit we moved more quickly with Dr. Force’s case than normal. But that doesn’t change his condition. I also know there is nothing we can do now, but carry out the decision that’s been made.”

“You can always refuse,” Alvirez says. “What can they do?”

“End my career,” Peabody says. “Brand me a renege. Make me too toxic to hire.”

“Let’s get some coffee,” Alvirez says. “I have an idea, if you’re willing to hear it.”

“Okay,” Peabody says, “and sorry again for the dunderheaded comment.”

I wish they'd take the damn tape off my eyelids. It itches, and I couldn't see Alvirez. It seems silly to say that. I have less than 24 hours, and I still don't know how I feel about it. I wish I could see. Someone grabs my arm and leg and turns me on my side.

"What are you doing?" a woman calls out.

It sounds like she's in the hallway outside my room.

"I'm giving him his sponge bath and then the orderly and I will change his linens," the woman holding me says. "It looks like he's developed a bed sore on his back."

"Forget it. He'll be gone tomorrow. They're withdrawing life support," the other says.

"Oh, I didn't know," the woman in the room replies as she drops her hold on me. "That's sad."

"The only other treatment he will get is a big shot of morphine," the woman in hallway adds. "It's standard procedure. We wouldn't want him to feel any pain. To tell the truth, I'm not sure the morphine won't kill him. Some of the doctors feel it's more humane than letting nature take its course."

Looks like wherever I'm headed, I'm going dirty. What would Daria say; 'not with me.' I can hear her. Of course, the only question about my destination is whether I'm planted in the ground or sprinkled on top of it. Surely it's the latter. These folks won't spring for a pine box and my older brother certainly won't. Why should I care? I'll be dead. I have to concentrate. Once they deliver the morphine, I'm as good as gone.

"So what you're saying is that if we stop putting the ointment on his eyes and we let them dry out so they're normal, if he's conscious he could cry to communicate with us," Peabody says.

"Yes. If he's aware of what's happening, he's terrified. He would have to be," Alvirez says. "Even completely locked-in patients may be able to cry. But actually this idea came from an Alfred Hitchcock Presents television series in 1950s. When I was in med school I was curious about locked-in syndrome after I saw a case in the hospital. A professor recalled seeing a Hitchcock show in which a man in a car crash is locked-in. He said it made such an impression on him he never forgot it. I Googled the TV series and found all of the shows in the Hitchcock series. In this one, rescue workers think the crash victim is dead and they send him to the morgue. Just before he's about to be embalmed, a tear streams down his face. The embalmer realizes he's alive and the show ends."

What are these two talking about?

"But how can we get him to cry?" Peabody asks.

"We'll tell him. If he's conscious, he'll have to," Alvirez says. "How often are his eyes moistened?"

"Every 12 hours," Peabody replies. "We just started taping his eyelids shut because they keep slipping open. He gets another application tonight. But the nurses know what we're doing tomorrow. They'll probably decide not to bother. I'd rather not write anything in his chart. Someone may ask questions later."

"Let's take the tape off and open his eyes," Alvirez suggests with a bit of excitement in her voice, "and just in case the nurses are more responsible than you think, I suggest you write in his chart that his eyes should not be treated. No one will notice such an innocuous entry. His eyes should dry out by tomorrow morning so that if he tears, we'll know he's conscious.

"Did you hear all this Dr. Force? You tell him Winston. He doesn't know me."

"I'm not sure about this," Peabody says. "It won't make a difference for him."

"It has to," Alvirez says. "If he tears tomorrow, the decision of the ethics consult was based on bad data. You cannot go through with the life support withdrawal. It would be unethical. Another consult would have to be held to consider whether life support should be withdrawn from a patient who is conscious, not one who is in a coma. We would have to determine the level of consciousness and try to communicate with him to find out if he can make his own decisions."

Alvirez removes the tape and my eyelids slowly rise.

"Okay. Here goes," Peabody says as he leans over me and peers into my eyes.

"Dr. Force, if you can hear me listen closely."

Brilliant, as if I have a choice.

"Dr. Alvirez…thinks…you…may…be…suffering…from…a…condition… called…locked-in…syndrome," Peabody says in very measured speech as if he were trying to help a non-English speaking person understand what he is saying by talking slowly.

"What are you doing, Winston," Alvirez asks. "If he's conscious, he'll understand normal speech."

"Sure. Sorry. Of course," Peabody says, sounding a little bewildered. "Dr. Force, we want to find out if you're conscious. One way of doing that is getting a signal from you. Obviously, if you had been able to communicate by moving or blinking, you already would have done it. There may be another way. We have been lubricating your eyes to make sure they don’t dry out. We will let your eyes dry out tonight. Tomorrow morning, when the whole team is here to withdraw your life support, we want you to cry, shed a tear. Do you understand?

“Winston, what do you expect him to do, nod his head?” Alvirez quips.

“I guess I’m a little nervous. If Sherman knew what we were doing, he would fire both of us on the spot,” Peabody says. “And I don’t believe anything will happen.”

“If it doesn’t, at least you’ll know,” Alvirez says. “I know I’ll feel better.”

They leave, and I have a new dilemma. Before I had only to decide if I wanted to let them kill me or fight, knowing that I was still going to die. It’s the same as having a terminal disease. Do you let cancer run its course or fight to the death?

Now I may be able to save myself. If I decline, am I committing suicide?

Morgan’s back. What is she doing? She’s crying.

“Dear Wilbur,” she says, caressing my forehead. “I came to say good-bye. I won’t be here tomorrow morning. I don’t think I could maintain my composure. I know it’s unprofessional of me as a chaplain, but I feel I’m too close to you. The re-emergence of feelings from so long ago, the connection I feel I’ve made with you through God, and my failure to help you are too much for me to watch you take your final breath. I pray God will welcome you.

“One thing I can do. I will make sure Sherman’s twisted plot is exposed. Please forgive Winston. In the end, he made the right decision. Goodbye.”

She kisses my forehead and winces as if my skin has a vile taste, probably the build-up of medicines oozing through my pores.

I wish I could talk with my former student; weigh the pros and cons of my new predicament. Surely, she would try to talk me out of suicide. It probably doesn’t sit right with her God. I have no such loyalty. My duty is to myself and no one else at this point in my life. No one will feel guilty if I die tomorrow. Alvirez has seen to that. She has contrived to eliminate her doubts, and Peabody’s, if he had any. She can tell the others of her scheme after I’m dead to relieve any twinge of conscience they feel.

‘I just want to let you all know,’ she’ll announce, after they record the time of death. ‘Dr. Peabody and I made one last scientific attempt to see if he was conscious this morning. He wasn’t. He wasn’t locked-in as I suggested. If any of you were worried, rest assured Dr. Wilbur Force was in an irreversible coma.’

Damn her, forcing me to make this decision. How do I know if I can cry? Suppose I decide to save myself and I can’t summon the tears? The extreme fear I’ve felt off and on since awakening should have unleashed a flood of tears. I could recall my sadness when Daria died. But I didn’t cry. She made me promise. I cried briefly when my mother died, but that was so long ago and I knew death was what she wanted. I’ve since banished the sadness of those memories. Surely the elation of knowing I was to be saved would open the tear ducts.

But do I want to live, cut off from the world? Maybe if they knew I was conscious, some method could be devised to communicate. Maybe Morgan would care for me. I’d want to get rid of this ventilator. I don’t want to be tied to it. I could wait to cry until they disconnect it and find out if I can breathe on my own. But how will the morphine affect me? It certainly will dull my emotions. It may kill me. How fast will they withdraw the medicines for my heart? Can I make myself cry on command?

Do I want to live? I must. Otherwise why would I try to figure out how?

I'm too agitated now, think.

My biggest curse is wondering what the moment of death is like. I try not to picture it, but the truth is it has intruded on me without warning since I awakened. Will it feel like a cold, grey, damp winter afternoon as the chemicals in my brain spit and sputter into inertia. Or is it like a fierce summer storm with a great bolt of lightning that rips across the sky as my neurons scream out in defiance. Maybe it's more serene like the sun dipping into the ocean as night falls, my mind having accepted its fate and calmly withdrawing from consciousness.

Then again, as the moment arrives rational thinking may vanish, an evolutionary instinct for survival seizing control to find an escape from the abyss.

Such speculation wastes time. It's already late at night. I must decide. I have three options. One is to agree to die and in so doing spend my last hours concentrating on the pleasant thoughts of my life, and engaging my imagination in speculation of what might have been had I been the person I always envisioned. I would hope for a warm, contented feeling to carry me through to the end like that which must have overcome 9/11 victims as they stood on a ledge high up in the World Trade Center and jumped, hand in hand, into tomorrow.

I could also decide to fight against death, and spend my final hours cursing the forces that conspired to bring me to this place; and in the words of Dylan Thomas "rage, rage against the dying of the light."

The third option is the most redoubtable. I fear by considering it, I accept it and then must decide to help effect my rescue or consciously prevent a tearful signal, thus committing suicide.

The nurse is back with another injection of medicine. I'm tired of thinking and the drugs make me sleepy, but I must decide something.

Perturbation

A noise awakens me. I can't tell if it's internally or externally induced. Someone's in my room. The blinds are raised. It's morning. But I'm still not prepared. Quick, what should I do? Yes, I want to live. I'll try to cry. I'll start right now. No I should wait to make sure I can breathe. Who cares? If it's life I choose, I can learn to live with anything. No, I want to die, restart the death cascade of two weeks ago that was halted without my permission.

They're here.

"Should we tape his eyelids shut before we proceed?" a woman asks.

"No," Peabody and Alvirez shoot back in unison.

"Who's going to extubate the patient and disconnect the other tubes?" the woman continues.

"I'll handle the life support withdrawal," Peabody says. "But I want to wait until Mrs. Chu arrives. I persuaded her to come and say a few words before we proceed. Let's record who's here. Dr. Alvirez will you handle that?"

"Yes. We have Wendy Turner, the head nurse; Michael Jurnegan, the LPN for this floor, you and me," she notes.

“I’m here,” Morgan calls out.

“Morgan, please proceed,” Peabody says.

“I contacted Dr. Force’s brother, but he has returned home,” Morgan says.

I’m lost. I can’t think. I feel as if I’m holding onto a ledge by my finger tips. Why not just let go? I’m frightened, but I don’t feel any tears welling, maybe I can’t cry. Maybe I don’t want to.

“I don’t have a traditional prayer for this occasion,” Morgan says. “I know Dr. Wilbur Force and he would not want any spiritual invocations. Suffice it to say he was, is, a good man, a mentor to hundreds of college students. When I knew him, he always showed respect for others and tolerance. Dr. Force was my college teacher. What I will remember most about him is his intellectual rigor. He poured his heart into his work, and he demanded the same from his students. Those of us who knew him are better for it.”

Morgan’s eyes are tearing as she leans over and kisses my forehead. I feel a few trickles hit my face. I sense her sadness, but it elicits no feelings in me. I’m glad, though, she is here. It doesn’t feel like they are administering the morphine. In fact, I’m feeling less drowsy. I’m alert. Maybe this is part of the plan to see if I will cry. But no emotions are stirring. Is it possible, I’m ambivalent about what’s happening to me? I see Peabody whispering to Alvirez. She walks away with her head down. He must have told her it’s over. I’m over.

“Thank you, Mrs. Chu,” Peabody says. “Wendy let’s give him 5 milligrams of morphine. Set up a drip of 2 milligrams of morphine every hour in case he continues to breathe and his heart keeps beating. If any of you want to leave, now is the time. I’ll remove the tracheotomy tube connected to the ventilator in about a couple of minutes. I want to let the morphine work to minimize any pain. Then I'll discontinue the blood pressure medicine and antibiotics. The last thing will be the IV line that's been feeding and hydrating him. I'll need one of you to stay here and record the time of death."

"I'll stay, doctor," a woman says.

The numbing effect of the morphine begins to wash over my brain like someone pulling a bed sheet over my head. I see through the haze. The forced air from the ventilator stops. I gasp. The pain in my chest is excruciating, but I start breathing on my own. I'm screaming so loud my head feels as if it's exploding. I see Peabody peering down at me. His expression is contorted. He's shouting something, my name I think. I feel him wipe his fingers under my eye. Am I crying? Did the pain force my eyes to water? I don't feel any tears. My lungs feel as if they're being torn apart. I hear others in the room shouting.

What's happening? I…I…

Acceptance

"What will you do with him now?" I hear a woman say.

"He's been breathing on his own for 24 hours," a man replies. "We've withdrawn the meds that were keeping his blood pressure stable, and you can see his heart beat and blood pressure are high. There's no telling how long his heart will last. We can't turn off the hydration and nutrition yet, not while he's still breathing. He should be dead soon. The morphine should have killed him."

"Why didn't you put in his chart that he cried? I was sure I saw tearing," the woman says.

“It would only complicate things,” the man says, “and besides I’m not sure the watering in his eyes reflected anything other than physical response to the shock his body experienced with discontinuation of the ventilator.”

“But you have to admit, Winston, it raises some doubt about whether he’s conscious,” she says.

“Maybe, but the hospital’s lawyer told me to contact the brother again and get permission to stop feeding him. It may be my last act here. The administration wants this guy to disappear, and me too, I fear. He represents a huge liability, given what Sherman was trying to do to him. Look we tried, but it didn’t work. It’s best for the hospital if we just let him die; and if he could tell us, I’m sure he would agree. Wouldn’t you Dr. Force? Dr. Force? Dr. Force try to make a tear if you can. Look Carmen, I can pinch his face and there’s nothing, no response. He’s gone. He’s not locked-in. He never was.”

Where am I? What’s happened to me? Peabody? Alvirez? What are you saying? I’m so dizzy. The last thing I remember…what’s that now? Who’s moving me?

“Where are you taking him?”

That sounds like Morgan. I feel as if I’m in a thick mud, so thick my thoughts are moving in slow motion.

“We have to move him to a step down unit, Morgan. We can’t leave him here in the ICU.”

“Winston, how long will he keep breathing?”

“I don’t know.”

Breathing, breathing…that’s me. I’m breathing. I’m breathing on my own. Oh, dear, that’s right, I remember now. I tried, but couldn’t summon the tears; at least I don’t think I could. I was too busy gasping for air and fighting off the morphine. I felt as if my body deflated, and then I must have blacked out. How long has it been? Did I hear 24 hours, and I'm still here? What now? Something's pushing into my arm.

"What are you giving him, Winston?"

"More morphine, we don't want him suffering. He may still feel pain, Morgan. I think it's time you moved on. Dr. Wilbur Force has occupied far too much of all our time."

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"How long has this patient been here?" I hear a man's voice say. "Two days since he was brought from the neuro ICU," a woman says. "He's a stroke patient in a coma with complete paralysis. He was removed from the ventilator, but he kept breathing on his own. The meds for his chronic hypertension were withdrawn, but his heart's still beating. His blood pressure fluctuates dramatically at times."

"If the decision was made to withdraw life support and let him die," the man says, "why is he still receiving nutrition and hydration?"

"His brother agreed to withdraw the life support, but the case is complicated. This is one of Sherman's test subjects, or would-be test subjects. Peabody had a change of heart," the woman says.

"Oh yeah, I heard, nasty business," the man says. "Has the brother been contacted about withdrawing the IV feeding tube?"

"The lawyers tried, but the ethics committee overruled the effort," the woman says. "The brother was paid off by Sherman for the decision to withdraw life support.

One of the chaplains made a big stink about letting the brother have any say in his care now."

"So what are we to do?" the man says. "I have two other patients waiting for beds in this step-down unit."

"The neuro-ICU folks say he can't hang on too much longer," the woman says. "His heart is bound to give out soon."

"Make sure the DNR order is posted on his door and over his bed," the man says. "I don't want some first year resident trying to revive him if he codes."

"There is no DNR," the woman says. "They never wrote one for him."

"I don't believe it," the man says. "We're supposed to resuscitate him if he codes? I'll take care of it."

"What about the bed sore on his back?" she asks. "It started to form in the last couple of days he was in the ICU. They did not treat it because he was scheduled for life support withdrawal."

"Leave it be," the man says. "Give him a sponge bath once a day, but no antibiotics. The morphine will keep the pain down, and if his heart doesn't give out, the infection will put an end to this."

Two days…hold off the morphine. If I could will my heart to stop, I would. I can't see. My eyelids are shut. The darkness and the fog in my mind create an odd feeling, as if I've become ethereal, like a gust of wind whose presence is known only by the rustling of leaves as it passes through a tree. What am I now?

Who's this? Someone holds my hand.

"Wilbur, I've come to say good bye," she says.

It’s Morgan.

“What have they done to your eyes? They’re sewn shut. Oh, I can’t believe it. This is why I have to leave. I want to cry seeing you like this. I can’t watch you die. These last two and a half weeks have been troublesome for me. The chaplaincy is transferring me to another hospital. I agree it’s a good idea. With all that’s gone on, it’s best I leave. Winston’s been placed on probation for a month and Sherman has been fired, along with Kopeckne. The whole affair has been turned over to the police. I hope they put them all away. The community is outraged. The news is filled with it. But that doesn’t mean much to you, I suppose. You don’t even know what’s been happening…goodbye.”

She kisses my forehead and leaves. I drift in and out of sleep. How long has she been gone? I can’t tell. The room is silent, nothing to hear or see. There’s a certain satisfaction in that. The pictures of my life are rolling, but not out of control. They don’t flood my consciousness like before. But I don’t recognize everything. Maybe these things I hoped for, but didn’t achieve and they were tucked away to avoid the angst, like some sort of neuronal coping mechanism.

I am sorry to hear Morgan leave. She recalls for me the best time in my life when I was satisfied, teaching, writing and loving. Daria and I were happy. There she is, I can see her, so pretty and enthusiastic. We enjoyed walks in the woods, sailing at the shore, quiet Sunday mornings reading…simple things. Her smile, there it is, always made me feel calm and content, a tonic for well-being. I hated when she died. I wanted to go first.

I wasn’t with her in the end. I deeply regretted that. She died in her sleep while I was away. I found her when I returned. I’m glad she’s not here to see me. I doubt she could take it. And I wouldn't want her to see what's become of me. I was strong for her, but her death left me wandering. I came to this city because it was one of our favorites. The warm air from the salt marsh always invigorated me. It gave me the same sense of calm I felt when Daria breathed on my neck as we slept. It was a feeling of security and of warmth that radiated throughout my body.

I don't want to think about my body now. It doesn't exist for me. I was trapped in that broken and deteriorating shell; now I'm free, free to fly on the wings of my thoughts.

What's that? I'm rolling. Someone's touching my back.

"What are you doing?" a woman says.

"I'm treating this awful bed sore," says the woman who's touching me. "Look at his fever. What antibiotics are you giving him?"

It sounds like Alvirez. What is she doing here?

"It's none of your concern," the other woman says. "The attending on this floor, Dr. Montgomery, said to leave him alone. He's a withdrawal. We need his bed."

"That's ridiculous," Alvirez says. "You're going to let the infection kill him?"

"If that's what it takes," the other woman says.

"Why don't you just shoot him with enough morphine to kill him?" Alvirez says. "Why are his eyes sewn shut? Where is this Montgomery?"

They leave; silence now. I'm still on my side. I don't feel the bed sore and fever Alvirez mentioned. Maybe I'm beginning to die. I'm quite prepared. How trite that sounds. I don't want to fight. I can't. I've lost. But I would like more time for another storyline. That sounds terribly odd; a dying man reaching out for one more piece of life. I'll just keep thinking.

There, that thought looks interesting. I don’t recall this experience. Daria’s here thank goodness. But who’s that little boy and the older girl. They look so happy. They’re ours? Look how much they’ve grown, she says, as if I’m seeing them for the first time in a long while. This is what might have been, children of my own, without memories of poopy diapers, terrible tantrums and the challenges and worries of two pregnancies, but also no recollection of the pride of birth and contentment of legacy.

I can’t think what this means; maybe regret buried deep in my brain. I was always interested in how my brain works, Poirot’s “little gray cells.” Now I think I know. I am within myself, a glove turned inside out. I am my thoughts. Everything I remember or imagine is a response to the world around me; of course, it is. What would I be without the outside world, without Daria, without students, without sunlight, without oxygen? What would I be if all my life I was shut off from the world, always looking inward?

“Dr. Montgomery, I strongly object to this,” Alvirez says.

“Who are you and what are you doing on my floor?” he says.

“I’m Dr. Alvirez. Dr. Force was my patient in the ICU until three days ago,” she says.

“You’re a first year resident. You don’t have any patients in the ICU, and you certainly don’t have any here,” he says.

“You can’t let him die of an infection,” she says.

“It’s not working anyway,” the man says. “His fever is up and his body is fighting the infection. I can’t imagine how. He should be dead.”

“If you don’t treat the infection, I’m going to the hospital ethics committee,” Alvirez warns.

“Go right ahead,” Montgomery says. “We just completed a consultation about this patient. The decision was made to withdraw nutrition and hydration, so he can die. We also implemented the DNR order you folks in the ICU should have written. I need this bed for people who have a chance to recover.”

If at first you don’t succeed, try, try again. How flippant. I feel a little inebriated. I don’t know if it’s the proximity to death, but I find myself unconcerned about the future, what little may be left of it.

I’d like to think I could have enjoyed a few more productive years in retirement. I was just getting started. Seventy-seven doesn’t seem too old. I was going to write a book, a novel about my life. Everyone has one book in them. Mine is about love, character, integrity and regret.

How will it feel to die of dehydration? That’s what happens when they remove the feeding tube. You don’t starve to death. How long will it take? Not long I suppose. Why don’t they just put an end to me with morphine? I’m not sure I would like that. Even in my condition, I’ll take a few more hours to think of opportunities.

I don’t know why, but I keep wondering what I look like, all shriveled and ugly, not even human, maybe something else. But what would that be? If I’m no longer part of humankind, what am I?

I can be whatever I want and what I want is to move at will through water, through air, through the earth, through space. If I were spiritual I suppose I should spend some time searching my gray matter for that ontologic imprint left by God, discover my true nature. But I’m not, so I’ll be on my way.

I’m weakening. Is it the dehydration? Too much philosophizing, I think. I wish I had a cheeseburger and a beer. I can smell it, that savory odor of cooked meat. And I can taste it, juices from the fat dripping down my chin. The beer is a little bitter, but it complements the meat. No, no, no catsup or mustard for me. They stifle the other flavors.

I hear someone in the room.

“This is Dr. Wilbur Force, Mr. Lonergan.”

It’s Alvirez. Who’s Lonergan?

“I’ve already filed an emergency injunction with the court to restore the artificial nutrition and hydration,” he says. “I don’t know what the hospital was thinking. As his court-appointed guardian, I can ask the judge to continue his other treatment as well, for the heart condition and for the infection. This poor man is being abused and it has to stop.”

“When is the hearing?” Alvirez asks. “The IV feeding tube was removed more than 24 hours ago. I fear he won’t last much longer; at most another day.”

“Tomorrow morning, July 18, is the earliest I could get the case on the docket. The hospital lawyers are objecting. Let’s hope he can hold on a bit longer,” the man says.

“Please leave immediately,” another man says. “Dr. Alvirez, I told you not to interfere.”

“Dr. Montgomery. What you’re doing isn’t right,” Alvirez says.

I barely hear the voices now. They sound as if they are far away in a tunnel. I think they’re gone. I’m so tired, but I don’t want to sleep, not just yet. I feel so heavy and it’s hard to breathe. But enough of that now, it’s time to travel.

I soar like an eagle, wings spread, riding an up draft high over the Rocky Mountains; what a view. Not a soul to be seen; just snow and rocks and blue sky forever.

How about a little deep sea diving? There, I've always wanted to see a thermal vent, with water bubbling turbulently. Further up, there's a coral reef. The water is so clear and the colors of the fish are so beautiful. They dart in and out as if playing a game of hide and seek.

Next stop the moon. It's so peaceful and there's the earth suspended in darkness, much like me. What's that I hear? It's the din of billions of voices leaking into the universe. Prepare for re-entry. I'm on my way to the center of the earth. What will I find?

I can't see anything. This is not what I expected. I was hoping to see the core; the beginning of time. But I'm trapped again, and fading. I think I'll sleep now.

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Epilogue

What is locked-in syndrome?

Wilbur Force suffers from locked-in syndrome (LiS), which may also be called pseudocoma or de-efferented state.[1] LiS is rare and is caused most often by a blood clot in the basilary artery that results in a stroke and damage to the brainstem.[2] The condition "was first defined in 1966 as quadriplegia, lower cranial nerve paralysis and mutism with preservation of consciousness, vertical gaze and upper eyelid movement."[3]

In most cases, all the patient's voluntary muscles are paralyzed, except for those controlling movement of the eyes and eyelids (blinking). The patient is conscious, can think, reason and is aware of his surroundings, but cannot move or speak.[4] The patient can see, hear, and feel, and understands what is going on around him.[5]

There are three different forms of LiS. In all three the patient is conscious. The "classic" version involves paralysis of all voluntary muscles except for the eyes. The patient can communicate by moving the eyes vertically or blinking. The "incomplete" version is similar to classic, but the patient may have some movement in addition to the eyes. The third form is "total" LiS in which the patient is completely immobile and unable to communicate.[6]

James Patterson and Martin Grabois write that patients suffering from the "total variety…are aware of both internal and external stimuli but are able to carry on only an internal monologue."[7]

Studies show LiS is difficult to diagnose and that misdiagnosis is common, especially when physicians are not familiar with the signs and symptoms.[8, 9] Misdiagnosed patients typically are thought to be in a coma, vegetative state or suffering from akinetic mutism,[10] a condition in which patients cannot move or speak as a result of injury to the frontal lobe portion of the brain. The incidence of LiS is not known, in part because of the rate of misdiagnosis.[11]

Neither computated tomography (CT) nor electroencephalogram (EEG) is considered reliable in diagnosing the brainstem lesions that cause locked-in syndrome. Magnetic resonance imaging (MRI) is preferred. However, even then the condition could be overlooked, unless the physician takes additional steps to determine if eye movement is voluntary and if the patient responds to questions.[12]

Another complicating factor that leads to misdiagnosis is that often patients "emerge from coma into a locked-in state after a variable delay."[13] Consequently in the early stages of the disorder, misinformed decisions may be made concerning care, such as withdrawal of life sustaining treatment.

In patients with total LiS, "rates of misdiagnosis are likely to be very high" and would require electrophysiological techniques to detect voluntary brain responses to external stimuli in assessing a patient's level of consciousness. In one such case it took nearly ten weeks to detect "the first sign of consciousness."[14]

Another study using positron emission tomography (PET) scans reveals hyperactivity in the amygdala of acute locked-in syndrome patients, but not chronic LiS patients. The authors note that PET scans of healthy volunteers associate "amygdala activation" with fear and anxiety. "We assume that the increased activity in the amygdala in acute, non-communicative LiS patients relates to the terrifying situation of an intact awareness in a sensitive being, experiencing frustration, stress and anguish."[15]

Because of problems in recognizing LiS, it can take months before the disorder is diagnosed. A 2002 study of 44 locked-in patients shows that average time to diagnosis from onset of the disorder was 2.5 months and in several cases was 4 years. The authors also note that in 54.5% of the cases, a family member was the first person to realize the patient was conscious, followed by physicians (22.7%), nurses (18.2%) and another individual (4.5%).[16] Patients participating in the study had been living with the disorder less than two years to more than 20 years, and the average was six years.[17]

Although locked-in patients suffer from severe restrictions in every phase of life, studies reveal that a significant percentage have a good sense of well-being.[18, 19, 20] The findings run counter to perceptions among the public, including medical professionals, that LiS patients generally would rather die than exist in their locked-in condition.[21]

In a 2011 study involving 65 patients, 72% were happy and 28% were unhappy.[22] More than 80% of the patients survived 10 years after their condition was stabilized.[23] In addition, the findings show that "depression, suicidal ideas, consideration or wish for euthanasia and the wish not to be resuscitated in case of cardiac arrest were significantly more frequent in the unhappy group."[24] Half of the patients in the happy group wanted to be resuscitated upon cardiac arrest compared with 14% among the unhappy group.[25]

The authors of the 2011 study also note that the patients surveyed were "cognitively intact" and therefore competent to make their own decisions about their care, including the withdrawal of life sustaining treatments or the desire for physician-assisted suicide.[26]

However, given the findings in their survey, the authors say, "We suggest that patients recently struck by LiS should be informed that, given proper care, they have considerable chance of regaining a happy life."[27]

This has not necessarily been the practice. A study in 2005 reveals that in the early stages of the disorder, when the patients are at their worst, "clinicians may often tend to comfortably assume that these persons will die anyway, or would choose to die if they only knew what the clinicians knew. As a result, debates about cost, daily management, quality of life, withdrawal or withholding of care, end of life decisions and euthanasia go on with prejudice and without input from the conscious but mute and immobile patient."[28]

The dilemma of balancing resources, patient autonomy and the extensive level of care required by LiS patients was debated in a *Hastings Center Report* commentary in 1985.[29] The commentators' arguments portend the broader debate today over the cost of health care with LiS patients representing among the most vulnerable and dependent on society.

Grant Steffan, an internist in Englewood, Colorado, concludes, "I feel that the quality of (the LiS patient's) life is minimal, the burden of his illness intolerable, and that life sustaining therapy should not be given…It is simply my intuition that the difference between the benefits of treatment – prolonged life – and the burden of that life is too great."[30]

Countering Steffan is Cory Franklin, director of the Medical Intensive Care Unit at Cook County Hospital in Chicago: "We should be prepared to care for these patients in the same way we care for spinal cord injury victims. (LiS) leaves (the patient) unable to represent himself, but does not divest him of his right to medical care…As the question stands, both on the basis of autonomy and appropriate medical care, (the LiS patient) is a candidate for vigorous life sustaining therapy."[31]

Notes

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Appendix

Ethics of Incapacitated Patient Care and Clinical Research

Trapped is a fictional story meant to dramatize ethical dilemmas involved in caring for terminally ill, incapacitated patients who cannot make decisions about their treatment, do not have advance directives, and do not have surrogate decision makers, such as family or friends, familiar with their wishes. In many cases, the patients are diagnosed by the attending medical professionals as comatose or in a persistent vegetative state with no hope of regaining consciousness. Further aggressive treatment is considered futile and withholding or withdrawing life sustaining care is recommended. *Trapped* depicts a stroke patient with locked-in syndrome who has been misdiagnosed as comatose, is completely paralyzed and unable to communicate, but is fully conscious and narrates the events surrounding his care as the medical professionals in the neurological intensive care unit (ICU) of a fictional hospital move toward withdrawal of life support.

Portraying Wilbur Force, the main character and narrator of *Trapped*, as a stroke victim suffering from total locked-in syndrome and misdiagnosed as irreversibly comatose, is the device used in the story to explore the ethical issues involved in caring for terminally ill, incapacitated patients without surrogates and without advance directives. Wilbur Force enables the reader to experience first-hand how one such patient is treated by narrating the events of the 12 days of his hospital stay.

The intent of the discussion in this appendix is to explore the scholarly commentary and research of three ethical issues raised by *Trapped*. The issues involve the treatment of terminally ill, incapacitated patients without surrogates and without advance directives, not patients with locked-in syndrome.

The primary issue discussed is withholding and withdrawing life sustaining treatment. In the absence of surrogate decision makers familiar with patients’ wishes or advance directives from patients, the best interests of the patient standard is usually the main test applied by third party decision makers, such as medical professionals, bioethicists and court-appointed guardians. In this discussion the severe shortcomings of the best interests standard will be examined, and another approach employing a cost-effectiveness measurement – quality adjusted life years (QALYs) - will be considered as an alternative for making treatment decisions.

The other two ethical issues – issuance of do not resuscitate (DNR) orders for terminally ill, incapacitated, patients without surrogates and without advance directives; and enrolling incapacitated patients in clinical research – are similar to the first in that the patients are not able to make decisions for themselves. In both instances, the best interests standard also figures in how decisions are made in U.S. hospitals. But in the discussion of these two issues, the main focus will be on proposing policies that employ a more standardized and systematic approach for making decisions than now exists in the U.S.

In addition, as each of the three ethical issues is discussed, its depiction in *Trapped* will be highlighted. The purpose in using fiction to discuss the ethics of incapacitated patient care and clinical research is two-fold. One purpose is to dramatize the subjectivity and inconsistency in the way decisions are made and to show the vulnerability of incapacitated patients without surrogates. The second purpose is to give a metaphorical voice to such patients by allowing Wilbur Force to explore his feelings about his condition and his inability to decide how he wants to be treated.

How Many Patients at Risk?

Before discussing the ethical issues, one question to consider is the number of patients in U.S. hospitals who are terminally ill, incapacitated, with no advance directives and no surrogates to make decisions for them.

Douglas White *et al.* describe their 2006 study as the first to provide a snap-shot of this patient population. Their findings show that of 303 patients admitted to the medical intensive care unit (ICU) of a metropolitan West Coast hospital over seven months in 2003 and 2004, 49 or 16% were incapacitated without surrogate decision makers and advance directives, and 13 of them died in the ICU during the study period.[1]

White and his colleagues in 2007 expanded their research to examine admissions to ICUs over six months in seven metropolitan hospitals in six states. They report that of 3,011 patients, 451 or 15% died and 25 or 5.5% of those who died were incapacitated and did not have surrogate decision makers or advance directives.[2]

A 2004 report by the American Bar Association estimates that "nearly 3 percent to 4 percent of the total nursing home population (in the U.S.) is unbefriended;" that is, people who have no families or friends to make decisions for them.[3] According to Kaiser Health State Facts, the number of people in nursing homes in 2010 totaled nearly 1.4 million,[4] making the unbefriended population during that year at an estimated 42,000 to 56,000.

As for the number of people with advance directives, a 2008 report to Congress from the U.S. Department of Health and Human Services observes, "Historically, only 18 to 36% percent of the adult population has completed advance directives."[5] In 2011, the number of adults (over the age of 18) totaled 235 million.[6]

These separate pieces of information provide some help in understanding the scope of the patient population under discussion here. In 2010, I undertook a survey of ethics committee files at a metropolitan Atlanta hospital to determine how many DNR orders were written for incapacitated patients without surrogates and without advance directives. In Georgia, physicians are required to consult with a panel of ethics committee members before writing DNR orders for these patients and they must sign a form attesting to the reason for the DNR order. The records of the consultations are maintained by the ethics committee.

Over 10 years, 130 incapacitated patients without surrogates and without advance directives were identified for ethics consultations. Ninety percent were ICU patients and most of the patients were in the medical ICU, one of five ICUs in the hospital. The survey was not designed to determine the total number of these patients treated at the hospital. But based on White’s studies involving metropolitan hospitals, the number likely should be much higher.

And based on the nursing home data and relatively low percentage of adults with advance directives, more studies are needed to assess the number of incapacitated patients without surrogates and without advance directives in U.S. hospitals; these studies would allow medical professionals to better understand the extent of this vulnerable population and issues surrounding its care.

Withholding and Withdrawing of Life Support

State laws, hospital policies, professional organization guidelines and individual physician practices vary significantly in the U.S. on making decisions for end of life care, including withholding and withdrawing life sustaining treatment from terminally ill patients who are incapacitated, have no advance directive stating their treatment wishes and have no family or friends to act as surrogate decision makers.[7, 8, 9]

According to Thaddeus Pope and Tanya Sellers, caring for these patients, arguably the most vulnerable in the hospital, is the "single greatest category of problems" facing ethicists, and yet most health care "providers are 'muddling through on an ad hoc basis.'"[10]

Many states have laws that address the care of such patients, but they are inconsistent. Some mandate that decisions should be made by the court with a court-appointed guardian representing the patients; others delegate the decision making power to physicians; and still others require review of physicians' decisions by ethics committees, either internal or external.[11]

An American Bar Association study concludes court appointed guardianship should be considered a process of last resort because "it removes basic human rights and can be costly and cumbersome."[12]

The American Medical Association, however, favors court involvement while the American Geriatrics Society warns against employing lawyers and instead recommends relying on hospital ethics committees.[13]

Some hospitals have created policies requiring physicians to consult with ethics committees before decisions are made. But even then physicians are not bound by the recommendations of the committees. And in some instances where decisions need to be made quickly, physicians "act as an informal ad hoc guardian…skirting legal requirements."[14]

Another troubling aspect of care for this vulnerable patient population is that few studies have been done on how many of these unbefriended terminally ill patients die in hospital intensive care units and how decisions are made about their treatment. In White's 2007 study, the authors' findings show these patients accounted for "approximately 1 in 20 deaths in intensive care units" and that "most life support decisions were made by physicians without institutional or judicial review."[15]

White's 2006 study concludes, "Physicians based (their) decisions predominantly on the patients' chances to survive the hospitalization, but also on more subjective criteria, such as patients' anticipated quality of life, their own perception of what was in the patient's best interest and concerns about appropriate resource allocation."[16]

The question of whether a court, hospital ethics committee, physician or some other group provides the most appropriate mechanism for making treatment decisions will be discussed later in the context of issuing DNR orders.

New Approach

In addressing the ethical issue posed by withholding or withdrawing life sustaining treatment from incapacitated patients with no advance directives and no family and friends to act as surrogates, the discussion here will focus on how the decisions are made. For whether the courts, ethics committees or physicians themselves make the decisions, the established legal and medical standard guiding them is best interests of the patients.

However, Marshall Kapp suggests the best interests standard is ill defined and involves too much subjectivity on the part of the decision maker. As a result application is inconsistent, meaning patients, through no choice of their own, will be treated differently depending on the intensive care unit they are in and who is in charge of their care.[17]

In addition, the best interests standard traditionally eschews consideration of the cost of patient care to society. This likely will have to change. The number of older patients in the U.S. is escalating dramatically, meaning that a greater number of patients will be decisionally impaired from illnesses such as stroke, cardiac arrest and Alzheimer's disease, and they will rely on surrogates, either family or friends, or third parties, such as physicians or the courts, to make decisions about their end of life care.

The U.S. is already struggling mightily to contain the high cost of health care, especially for the fast growing population of older patients covered by the federal government's Medicare health system, the nation's single largest health care payer. As the number of older patients increases, pushing taxpayers' costs ever higher to fund their care, Daniel Callahan notes government officials and economists predict the nation will face an economic disaster in 20 years.[18] The solution offered by Callahan and others is health care rationing for the elderly.[19,20, 21]

Faced with escalating health care costs, particularly among patients at the end of life, I propose that using a cost-effectiveness measure such as QALYs may provide an element of objectivity to offset the highly subjective best interests standard in making treatment decisions for incapacitated patients without surrogates and without advance directives.

In *Trapped*, the decision to withdraw life sustaining treatment from the main character and narrator, Wilbur Force, is discussed during an ethics consultation in which physicians control the decision making process and contend withdrawal is in the patient's best interests. Subsequently, the hospital chaplain, Morgan Chu, suggests the decision to withdraw life support is based not on Professor Force's best interests, but on the hospital's need to reduce expenditures. And unbeknownst to the chaplain the physicians involved have their own motives for ending Professor Force's life.

After exploring the concept and shortcomings of the best interests standard, the discussion here will examine studies that have applied cost-effectiveness measures in assessing treatment decisions for terminally ill patients in hospital intensive care units.

Best Interests

The principles of informed consent and patient autonomy in medical care are well established.[22] Terminally ill competent patients have the right to make decisions about their medical care, either accepting it or rejecting it, and to make those decisions they must be fully informed about their conditions and the risks and benefits of treatments.

In the case of terminally ill, incapacitated patients, who have no advance directives expressing their wishes about end of life care, the principles of informed consent and autonomy extend to family members or friends who act as surrogate decision makers. The surrogate makes decisions based on the substituted judgment standard; that is, the surrogate knows the patient well enough to attempt to make decisions on what the patient would want if the patient were able to communicate. In some instances these surrogates were empowered to make decisions by the patients themselves when they were competent. In others, the family members or friends are considered the best judge of knowing what the patients would want.[23]

Although surrogate decision making is widely endorsed, one study suggests family members and friends “cannot accurately predict patients’ preferences” and in effect the surrogates’ choices “are not much better than random chance.”[24]

Nevertheless, Robert Arnold and John Kellum say family members and friends are likely to be better predictors of patients’ preferences than health care providers or the courts, which employ the best interests standard in making decisions for incapacitated patients.[25]

The best interests of the patient standard is based on the ethical principles of beneficence and non-maleficence.[26] It is applied when incapacitated patients have no advance directive expressing their wishes and have no family members or friends to act as surrogates in making decisions.

Third party decision makers such as physicians, court appointed guardians and ethics committee members cannot possibly know patients’ preferences. Instead, they apply the best interests test in an attempt to balance the benefits of treatment against the burdens it causes the patients. In other words, the benefits of initiating or continuing life sustaining treatment for a terminally ill, incapacitated patient would be balanced against the burdens to the patient of being kept alive artificially with no social interaction, no quality of life and continued exposure to pain and other serious illnesses. In judging benefits versus burdens, the decision makers apply the reasonable person standard. Given the assessment of benefits and burdens what choice would a reasonable person make under the same conditions? Would she continue life support or choose to die naturally?[27]

Despite a goal of objectivity, Kapp notes commentators have criticized the best interests standard as “inherently subjective.”[28] One study shows physicians, who are often the third party decision makers applying the best interests standard, “systematically” rate patients’ quality of life lower than patients do themselves and physicians project their own value judgments on their patients.[29]

George Tomossy and David Weisstub conclude: “Both the best interests and substituted judgment standards rely intrinsically on value judgments made by a person other than the incompetent adult for whom the decision is being made. The former involves an external assessment and balancing of interests, while the latter requires the decision maker to ‘stand in the shoes’ of the incompetent person, an act that is in fact rooted in fantasy. The difference is purely semantic, and in reality, any decision made for a mentally incompetent person will inevitably rely on a combination of the two patterns of decision making.”[30]

Despite the criticism of the best interests standard in dealing with incapacitated patients, it is routinely applied in hospital intensive care units across the U.S. Kapp suggests that charges of subjectivity and inconsistency in applying the standard are “unreasonable” in that “surrogate decision making cannot follow a rigid formula or algorithm…(and) so long as the varying results of the decision making process fall within an ethically acceptable range, those results and the process that produced them ought to be legally permissible.”[31]

However, the intention here is to suggest a strategy for offsetting, where possible, the shortcomings of the best interests standard by applying a more objective measure to assess both the health outcomes from aggressive care for terminally ill, incapacitated patients and the cost to the health care system. The cost-effectiveness measure to be applied is the QALY.

Cost-Effectiveness Approach

Calculating QALYs has become the “gold standard” in measuring cost-effective health care outcomes.[32]

As their architect, Alan Williams, explains: “The essence of a QALY is that it takes a year of healthy life expectancy to be worth one, but regards a year of unhealthy life expectancy as worth less than one...If being dead is worth zero, it is in principle, possible for a QALY to be negative, i.e., for the quality of someone’s life to be judged worse than being dead.”[33]

The logic in this description is similar to the balancing test in the best interests standard, but with a quantitative approach. QALYs do not just measure the effectiveness of a health care treatment to keep a patient alive, they also factor in the quality of life gained. In addition, calculating QALYs includes the cost of the treatment. “The general idea,” Williams says, “is that a beneficial health care activity is one that generates a positive amount of QALYs, and that an efficient health care activity is one where the cost per QALY is as low as it can be.”[34]

The attractiveness of QALYs is that they account for quality and length of life gained from any health care activity with consideration for the distribution of limited resources.[35]

What are the implications for end of life care? Currently, they are more theoretical than empirical. “Overall, there is a paucity of cost-effectiveness analysis on management of the critically ill” in the ICU, although estimates are that “ICU costs represent up to one third of all hospital costs.”[36]

In addition, one study of 131 ICUs in 138 institutions in 38 states shows that limiting life support by withholding or withdrawing treatment was “so commonplace as to represent a *de facto* standard of end of life care for critically ill patients.”[37] But the study also reports “extreme variation” in how patients were treated, suggesting a “lack of consensual guidelines for end of life care.”

One implication then for use of cost-effectiveness measures in assessing end of life care would be to provide quantitative data for more consistent management of all critically ill patients in ICUs.

But the discussion here is focused specifically on terminally ill, incapacitated patients with no advance directives and no surrogates to represent their wishes. In managing the care of these patients, having data about the effectiveness of interventions for the patients and the cost to the health care system could add more objectivity and consistency to the decision making process.

In one 2002 study, researchers measure the cost effectiveness of “aggressive treatment of patients with non-traumatic coma, as opposed to withholding CPR and ventilator support by day 4 of coma.” The analysis is based on data from patients who participated in the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments, conducted from 1989 to 1994 at five academic medical centers.[38]

The patients had different risk factors related to their prognosis and were classified in two groups, low risk and high risk. “For the low risk patients, 1-year mortality was 58% for patients receiving more aggressive care and 95% for patients receiving less aggressive care. For high risk patients, the 1-year mortality was 95% for patients receiving more aggressive care and 99% for patients receiving less aggressive care."[39]

The cost per QALY for patients in the high risk group was $140,000. For patients in the low risk group, it was calculated at $87,000. Although the U.S. does not officially use QALYs to make treatment decisions, the general consensus among health care professionals is that a broad range of $50,000 to $100,000 per QALY is acceptable.[40]

In another study in 2007, researchers examine data from critically ill patients in the ICU who received prolonged mechanical ventilation for more than 21 days compared with patients who were withdrawn from the ventilator between day 7 and 21. The patients were removed from the ventilator with the expectation they would die. The researchers calculate that "providing mechanical ventilation for 21 or more days to the 65-year old base-case patient gained 2.593 life years or 1.75 QALYs at a cost of $143,000 compared with ventilation withdrawal. The difference in life years gained and QALYs gained reflects the difference in quality of life assessment. The cost per QALY was $82,411 for prolonged mechanical ventilation compared with withdrawing ventilation.[41]

The authors note that the cost per QALY increased with age, reaching $162,000 per QALY at age 80. They conclude their analysis shows "that prolonged mechanical ventilation is associated with low cost effectiveness among the elderly and those with a low likelihood of 1-year survival."[42]

The usefulness of QALYs to help inform third party decision makers in considering whether to withhold or withdraw life support from terminally ill, incapacitated patients will depend on what the U.S. and state governments would consider an acceptable cost per QALY to pay for end of life care for Medicare beneficiaries and the poor covered by Medicaid insurance. A range of $50,000 to $100,000 seems much too broad. The U.K.'s National Institute for Health and Clinical Excellence (NICE), which judges the cost-effectiveness of treatments for patients covered under the nation's universal health care program, limits treatment reimbursements to a range of $30,000 to $45,000 per QALY.[43]

Reaching a consensus on a threshold cost per QALY is not the only controversy when it comes to considering use of QALYs in end of life care. There is considerable disagreement on whether QALYs should be used at all to assess treatment of terminally ill ICU patients.

Controversy over QALYs

The main controversy focuses on the value of time for terminally ill patients. QALYs calculate the quality and length of life gained by health care treatments. Critics contend that the value of time is greater as death nears because there is less of it and therefore QALYs should not be used.[44]

"If time is not valued the same at the end of life as it is at other times," as critics charge, "(then) it would not be possible to simply sum the QALYs gained from an intervention to estimate the total welfare."[45]

In the U.K., NICE has dealt with the controversy by agreeing that time is more valuable at the end of life and has authorized paying for certain end of life treatments above its threshold range.[46]

Jeff Round says commentators who favor applying QALYs to end of life care argue that some sociological research suggests that the value of time in childhood is more valuable than other stages of life. If society decides time at the end of life is more valuable, Round suggests, “It would need to be demonstrated that favoring this health above other health (such as that of children) does not lead to an inequitable distribution of resources.”[47]

Another major element of the debate is that people have different opinions on what constitutes good and bad quality of life. Aside from trying to achieve a more equitable distribution of resources, the premise for using QALYs is that people would prefer living a shorter time in good health as opposed to a longer time in ill health, which means that a gain in QALYs is not solely determined by an extension of life; a gain can also be achieved by an enhancement of life.

Still, there is no question people have different opinions of what constitutes a good quality of life. John Harris says, “It does not follow that where the choice is between three years of discomfort for me or immediate death…and one year of health for you or immediate death, that I am somehow committed to the judgment that you ought to be saved rather than me.”[48]

Applying QALYs systematically to end of life care will require research to collect empirical data on the opinions of adults, regardless of age, of what constitutes quality of life as death nears and how they value quality of life versus the value of extending life. This data could be incorporated into the QALY calculation and help support public acceptance of this cost-effectiveness measure for the benefit of patients and a just distribution of resources.

In one study of patients more than 80 years old, when the cost of QALYs likely would be highest, only 30% wanted care to prolong life.[49] This may suggest that a better system of educating people about embracing advance directives and living wills could reduce decision making problems for incapacitated patients without surrogates.

However, with only 18 to 36% of adults embracing advance directives, applying QALYs in determining end of life care for terminally ill, incapacitated patients without surrogates may be a way to offset the subjectivity that now exists. Although critics may charge discrimination against these vulnerable patients if QALYs are not applied to all patients, the same charges could be leveled against the best interests standard, which studies have suggested is no standard at all because of its inconsistent application from hospital to hospital and from physician to physician.[50]

Incapacitated patients without surrogates and advance directives already face discrimination based on their inability to communicate. Applying QALYs, backed by empirical evidence of society's opinions on quality and length of life, may be a way of giving this patient population a voice.

Do Not Resuscitate Orders

In writing DNR orders for terminally ill incapacitated patients without advance directives or without family members or friends to acts as surrogate decision makers, third party decision makers, such as physicians, ethics committees and court appointed guardians, apply the best interests standard.

The same inconsistency in applying the best interests standard to withhold or withdraw life support exists in deciding whether or not to write a DNR order. Only a handful of states have laws governing implementation of DNR orders for incapacitated patients without surrogates and the statutes vary from state to state.[51] Professional medical societies differ in who should have authority to make the decisions.[52] Policies also vary from hospital to hospital.[53]

In addition, DNR orders are not well understood by medical professionals. They apply only to cardiopulmonary resuscitation in the event of cardiac arrest. However, some studies have demonstrated that “based solely on the presence of a DNR order, physicians are less likely to agree to initiate procedures ranging from complex therapies (such as those requiring ICU admission), to simpler interventions, such as blood transfusions.”[54]

In *Trapped*, the ethical issues involving DNR orders are raised by Dr. Harold Sherman, the attending physician for Wilbur Force; the hospital chaplain, Morgan Chu; and another physician, Dr. Montgomery. Dr. Sherman believes physicians should have the responsibility of writing DNR orders for incapacitated patients without surrogates because physicians are the best judge of patients’ medical conditions. Mrs. Chu raises the issue of how DNR orders are misinterpreted by medical professionals, and Dr. Montgomery shows the role DNR orders play in withholding or withdrawing life sustaining treatment.

This discussion with respect to DNR orders focuses on the process or mechanism for writing DNR orders. The suggested recommendations for improvement also could apply for making decisions to withhold or withdraw life support from terminally ill, incapacitated patients without surrogates and without advance directives.

In White’s 2006 study, the findings show that “decision making practices for (incapacitated patients without advance directors or surrogates) generally involved decision making solely by physicians" and the authors worry that this approach does not ensure "that decisions for these patients are fair and consistent.[55]

White's second study in 2007 reveals decisions to write DNR orders were made by ICU medical teams or the attending physician alone and that hospital policies were ignored.[56]

The recommendation of this author is to empower hospital ethics committees to make decisions about DNR orders as well as withholding or withdrawing life sustaining treatments for incapacitated patients with no surrogates. To ensure protection for these patients and maintain a consistent decision making process, at least within each state, the committees also should be regulated either by state government or an independent organization, and the make-up of committee members should be multi-institutional and multi-disciplinary.

These recommendations would be a significant change in the operations of hospital ethics committees. Beginning in 1992, the Joint Commission that accredits and certifies health care organizations required hospitals to have ethics committees. Accreditation is a prerequisite for receiving Medicare and Medicaid reimbursement and it is required for licensing in many states.[57]

However, most hospital ethics committees do not have the power to make decisions on the care of patients. Their role is as reviewer and consultant for the attending physicians. These limitations are supported by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research despite its 1983 endorsement of the use of medical ethics committees in a report titled, "Deciding to Forgo Life Sustaining Treatment."[58]

The Commission says it “is not recommending that hospitals and other institutions take over decisions about patient care; there is no substitute for the dedication, compassion, and professional judgment of physicians. Nevertheless, institutions need to develop policies because their decisions have profound effects on patient outcomes, because society looks to these institutions to ensure the means necessary to preserve both health and the value of self-determination, and because they are conveniently situated to provide efficient, confidential, and rapid supervision of decision making.”[59]

Although some states have laws governing the process for making decisions about patient care, the vast majority do not address the issue of decision making for incapacitated patients without surrogates.[60] A few of the states that do address this issue require court appointed guardians to act as surrogates for the patients.

However, one study shows that end of life decisions, such as writing DNR orders, often were made while awaiting court appointment of a guardian, and when guardians were appointed “only 32.4% of patients had chart documentation indicating that a member of the medical team had some type of contact with the court appointed guardian.”[61]

Empowering hospital ethics committees to make decisions for incapacitated patients without surrogates should help ensure that the best interests of these patients are being considered. The committees also could be the mechanism for assessing the appropriateness of employing QALYs in the decision making process.

State regulation of the committees would provide several safeguards for patients. It could mandate that ethics committee members are trained in ethics and represent a diversity of disciplines and perspectives. It could also stipulate that the committees include members not associated with the hospital.

Enabling ethics committees to make decisions should help eliminate the shortcomings and flaws of physician decision making. “The very birth of bioethics,” one commentator says, “was based in the idea that some health care decisions are too complicated and momentous to be left in the hands of physicians alone.”[62]

Thaddeus Pope compares the evolution of ethics committees from good idea to essential role in medicine to that of alternative dispute resolution (ADR) in law. ADR was devised to handle disputes by methods other than litigation, creating a mechanism for efficient and inexpensive resolution of some civil and criminal cases. Pope says, “Scholars have described the growth of ADR as falling into three developmental stages: (1) experimentation, (2) implementation, and (3) regulation. That model can be adapted to ethics committees: the experimentation stage, from roughly 1975 to 1992; and the implementation stage, from roughly 1992 to 2010. It is time now to move to the regulation stage.”[63]

Until unilateral decision making is taken out of the hands of physicians for incapacitated patients without surrogates, these patients will continue to be subject to inconsistent care that is often not in their best interests.

In the next section, the discussion will focus on the ethical issue of enrolling terminally ill, incapacitated patients in clinical research.

Research with Incapacitated Patients

Human subjects' research in the U.S. is tightly regulated by the federal Common Rule (Code of Federal Regulations, Title 45, Part 46) and the Food and Drug Administration, which oversees clinical research of medical interventions.[64]

The Common Rule does not specifically address research involving mentally disabled, incompetent or incapacitated patients. However the FDA permits emergency medical research on patients who are unable to provide their consent. "The research is permitted if subjects are in a life-threatening situation, available treatments are unproven or unsatisfactory, and the collection of valid scientific evidence is necessary to determine safety and effectiveness of particular interventions; and the intervention must be administered before any legal representative can make a decision." The regulations do not address research of incapacitated patients in non-emergency situations such as critical care in the ICU.[65]

In general, however, research involving decisionally impaired or incapacitated patients in the U.S. requires the informed consent of a legally recognized surrogate decision maker and the research should provide the prospect of benefit to the trial subject with minimal risk.[66] The latter requirement for an expectation of direct benefit does not apply to clinical trials involving patients who voluntarily consent to participate. Potential benefit to participants is not required.[67] However, risks should be minimized and reasonable "in relation to anticipated benefits, if any, to participants, and in relation to the importance of the knowledge that may reasonably be expected to result."[68]

The European Union (EU) issued a 2001 Clinical Trials Directive that included guidelines for research involving incapacitated patients. They are similar to what is generally acceptable in the U.S. There are nine additional requirements to the five governing protections for research subjects who are able to consent to participation. The additional restrictions include mandating informed consent from a legal representative of the incapacitated patient; and expectations that "administering the medicinal product to be tested will produce a benefit outweighing the risks or produce no risk at all.[69]

One of the major criticisms of the EU directive is confusion over the restriction that the research should provide an expectation of benefit to the incapacitated patients, whose participation also is governed by the five general protections. The general protections permit clinical trials for patients who consent to participate even though they will not benefit; as long as the "risks and inconveniences have been weighed against the anticipated benefits for the individual trial subject and other present and future patients...and the anticipated therapeutic and public health benefits justify the risks."[70]

The confusion for European researchers is that the directive is unclear whether surrogate decision makers can consent to enrolling incapacitated patients in trials that have no expectation of benefit for them, but may benefit other and future patients suffering from the same condition.

In *Trapped*, the ethical issue involved in conducting clinical research on incapacitated patients is raised by Dr. Harold Sherman who wants to test a new drug on Wilbur Force that will not benefit him. The physician's motive is greed, but he also discusses the potential benefits of the research for future stroke patients.

The proposal in the discussion here is that research with incapacitated patients should not be restricted by expectations of benefits for the trial subjects, and should be permitted based on expectations of benefits to the broader population of patients with the same condition. In other words, the risk-benefit analysis of the research should include not only the best interests of the patients enrolled in the trial, but also the best interests of the broader population of current and future incapacitated patients.

The assessment of the best interests of patients concerning research is not the same as the best interests with respect to medical treatment. The risks of participating in research, which can involve such elements as unproven medicines and placebo-controlled randomized trials, many times may not be in the best medical interests of the patient.[71]

The role of the surrogate decision maker in research also is different from the role of surrogate in making medical treatment choices. Even if family members or friends do not know patients' specific wishes regarding treatment, they likely can infer patients' preferences from past treatment experiences and in previous conversations about medical treatment. Most people are not involved in research so surrogates are much less likely to have an opinion when trying to decide if patients would want to enroll in clinical trials.[72]

The differences between medical treatment and research with regard to the best interests standard and the role of surrogates are key reasons why research with incapacitated patients has been limited to trials in which there is an expectation of benefit for the research subjects.

Without federal regulations governing research with incapacitated patients in non-emergency situations, it would seem unwise to advocate for such research when it does not involve the expectation of direct benefit. The potential for abuse likely is greater than in studies that demonstrate an expectation of direct benefits. Yet discouraging research whose anticipated advances in medical care are not directed at trial subjects but to the broader population of existing and future patients will certainly continue to impede progress on finding new treatments for such conditions as mental illness, stroke, severe head injuries and cardiac arrest.

The authors criticizing the EU restrictions on research with incapacitated patients note, “There is much uncertainty about the clinical utility and side effects of drugs used to stabilize or treat mental illness. We have no specific treatment for 97% of people who suffer from a stroke. More than 50% of people who suffer from severe head injury die or remain seriously disabled for the rest of their lives, and more than 90% die following out-of-hospital cardiac arrest.”[73]

The intent here is to suggest an ethical framework for a public policy that embraces research with incapacitated patients even though they may not receive direct benefit. Carl Coleman describes such a framework relying on the assumption that there are “two levels of best interests,” a strategy that he contends ethically supports “broadening the risk-benefit assessment beyond the level of the individual study.”[74]

The first step involves assessing the risks and benefits of a study to determine if it is in the best interests of the incapacitated patients to enroll. The second step involves assessing the risks and benefits from a broader perspective that includes consideration of other and future incapacitated patients.

“Here,” Coleman says, “the relevant question is whether it is better or worse for incapacitated people *to be governed by a policy* that permits surrogates to consent to (such) studies.” His point is that even if it is not in the best interests of patients to be enrolled in a specific study (that is, there is no expectation of a direct benefit), it may be in their best interests to be subject to a policy that allows surrogates to make such decisions. The balancing test is to assess whether the risks of being exposed to the policy are lower than the benefits to be gained from the research, which could not be performed without the policy.[75]

In other words, public policy should recognize that prohibiting incapacitated patients from participating in no-direct benefit research, means they also will never benefit from studies that are not permitted.

Coleman explains that the policy does not discriminate against incapacitated patients by enabling them to be enrolled in research when competent patients face no such obligation. The reason is that for research involving competent patients, there are enough potential voluntary subjects.

“By contrast,” Coleman says, “important research on capacity-impairing conditions could not be conducted if we limited such research to individuals whose desire to participate could be clearly established.” If it were, incapacitated patients would suffer by never benefitting from medical progress.[76]

Coleman says the research also should “offer benefits that otherwise would be unattainable” and should be restricted to benefits specifically for the population of incapacitated patients under study. In addition, incapacitated patients should have access to any treatments developed regardless of whether they participated in the research.[77]

As for risks, Coleman says incapacitated patients enrolled in research that will not benefit them should face no more than minimal or moderate risks, which would be outweighed by “the benefits those persons are likely to receive from similar research conducted with other incapacitated people.”[78]

Another element of the policy should be to explicitly prohibit any research on incapacitated patients without surrogates or without an advance research directive indicating their willingness to participate.

Coleman acknowledges his argument for enrolling incapacitated patients in no-direct benefit research could be interpreted as a way for bypassing all together the need for surrogate consent. But in addition to removing one of the safeguards for such research, he says, “Conscripting incapacitated persons into research without even asking their families just seems offensive.”[79]

Finally, implementation of a policy allowing no-direct benefit research with incapacitated patients involves three other steps. The first is that a federal agency (such as the FDA) would have to adopt regulations, which could be modeled after the guidelines for research with children. Second, institutional review boards on the local level would review the research protocol for compliance as they do with all human subjects’ research. The third step involves crafting informed consent statements for surrogates that clearly state the participating patients will not necessarily benefit from the research, but the expectations are that other patients with the same condition may benefit.[80]

Coleman’s ethical framework counters the argument that incapacitated patients enrolled in research that will not benefit them constitutes a serious breach of the Kantian notion of respect for persons in that such research forces certain incapacitated patients to be exposed to risks for the benefit of others. However, having a policy that enables such research with the consent of legally recognized surrogates increases the possibility of benefits for all incapacitated patients. The greater risk is that prohibiting such research ensures the likelihood these patients would never benefit from medical progress.

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