



University of Miami Bioethics Bowl 2015 Case Packet

March 29, 2015

Please note that each case contains 3 questions,
but only ONE will be asked during the
competition.

Good luck with preparation!

(Adapted from the 2014 National Undergraduate Bioethics Conference Case Packet)

CASE 1: “Debarking” an Autistic Boy

The Hanegraafs were struggling to treat their autistic son’s vocal tics when they finally found a doctor who could help them. Kade was fourteen years old at the time and his tics were severe. He screamed upwards of 2000 times per day at a volume of 90 dB, about the same level as a motorcycle’s engine, and he had been doing so for over three years. The tics were taking their toll on the boy, his parents, and his twin brother (also autistic) who is sensitive to noise. The doctor and the boy’s parents decided the boy would undergo thyroplasty, a surgical operation that would soften the boy’s voice. The procedure has been likened to the devocalization of pets, especially dogs, sometimes called, “debarking.”

Two years after the surgery, Kade’s doctor, Dr. Dailey, published a medical report on the case and it began receiving media attention. Autism advocates, many of them adults with autism, were dismayed and disgusted by news of the procedure. Advocate Lydia Brown wrote, “There are other ways to address the issue than forced surgery... The surgery was performed because Kade was an inconvenience to his parents....This is torture.”

Ari Ne’eman, co-founder of the Autistic Self-Advocacy Network, was also staunchly opposed to the procedure and made this public statement on behalf of the network:

Autistic people and others with communication related disabilities often use what’s termed as ‘problem behavior’ as a way of communicating distress, anger, fear, anxiety or other important emotions that may not be easily communicated for someone without standard speech. There is a long history of family members and providers viewing these behaviors as strictly a medical phenomenon and not recognizing they’re important for communication. To violate a person’s bodily autonomy and damage their ability to communicate to serve the convenience of the caregiver is nothing short of horrific. We view this as similar to the Ashley X case or the long history of involuntary sterilization, teeth removal and other inappropriate and unethical medical procedures conducted against people with developmental disabilities.

Steve Silberman, a writer on autism, also worried that this was another example of a historical inability to cope with the atypical behavior that sometimes accompanies disabilities. “If your kid had a problem with ‘wandering,’ would you surgically hobble them?” Silberman asked, adding that “treating autistic people like dogs that need to be debarked is grotesquely inhumane.”

Dr. Dailey’s report claimed that six months after the operation Kade’s tics had reduced in frequency by ninety percent and in intensity by fifty percent. The doctor claimed Kade was showing signs of improvement in his social interactions, his educational development, and his nutritional health. Dailey spoke on behalf of the Hanegraaf’s claiming that it was not only the boy’s parents and brother who were tormented by his screams, but Kade himself suffered. He couldn’t go to school, develop friendships, or maintain a supportive system of caregivers because of his outbursts. The Hanegraafs claimed Kade couldn’t even eat a full meal without screaming.

Kade's mother claims the operation was a miracle and that it would have been unethical to refrain from the surgery. "When you see it trickle down to his brother, this was a life sentence," she said, "I didn't see my son smile for three and a half years. Now, he has a whole new life inside him."

Questions:

1. If the surgery on Kade was done for the convenience or benefit of Kade's parents and his brother, and not solely to benefit Kade himself, does that make the procedure ethically wrong?
2. Some medical procedures requested by parents on behalf of their children are seemingly not morally problematic. How should we distinguish those procedures that are morally problematic from those that are not? According to your criteria, is Kade's thyroplasty morally problematic?
3. Evaluate the decision made by the Hanegraafs and Dr. Dailey. Was their decision and the reasoning that led to it ethical?

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CASE 2: Faith and Brain Death

Nailah Winkfield checked her thirteen year-old, Jahi McMath, into Children's Hospital Oakland to undergo complex tonsillectomy surgery. After the procedure, Winkfield and other family members were talking with McMath when the child began spitting up blood. McMath was bleeding heavily; within three days she suffered cardiac arrest and "whole brain death." Soon after, the family was notified that the child was legally dead and should be removed from life support. Winkfield and family resisted the hospital's appeal to remove life support and for the next several weeks they battled the hospital in court to get permission to maintain life support and have the child transferred to another facility.

The hospital claims the child has no chance of recovery, but McMath's family holds out hope that God may yet heal the girl. Their experience touching her in her hospital bed, even weeks after being declared dead, leads the family to believe she still has some life left in her.

The safest method of transfer would require the hospital to perform a tracheostomy and place a feeding tube in the patient. But as two hospital physicians, three outside physicians (selected by the family), and one court appointed neurologist have all declared the child to be brain dead, the hospital refuses to perform the procedures. The court granted permission to Winkfield to take full responsibility for moving the child on the ventilator, but it did not require the hospital to perform the requested procedures.

"I will always fight for Jahi until she is ready to go, her own self. I can't play God. She's going to get better or she's not, but I see her getting better," Winkfield told reporters after the court adjourned, according to the *San Francisco Chronicle*.

Though the family is out of court for now, the California Board of Public Health is investigating the case. As disagreements of this kind, between families and hospitals, are not uncommon, it's unclear what went wrong in this case. The family was quick to get a lawyer and go public, and the hospital followed suit, largely worried about public relations. There is some reason to suppose the hospital mishandled the case. In the midst of the court battle, Winkfield told CNN:

They have not given me a reason yet of why she went into cardiac arrest. They haven't even given me a reason for her bleeding. They haven't given me a reason that they couldn't stop the bleeding... The only thing they keep pushing for me is to get her off their ventilator.

It's unclear how long McMath will be kept alive on the ventilator. The family's lawyer announced that they have found a facility and physician willing to continue to treat the child, but they have not announced further details about the transfer.

"No matter how much medical evidence we present to the family, if they have a faith that dictates things, it's hard to overcome that," said Dr. Richard Boudreau, a bioethics expert.

Questions:

1. If you were the bioethicist assigned to this case, how would you have counseled Winkfield and her family after learning that they refused to remove life support?
2. Is educating the public about the medical distinctions between brain death, persistent vegetative state, and coma a moral necessity? Such education would seem to aid in understanding the legal outcomes in this case, but would it aid in understanding the moral issues as well?
3. How should Winkfield's (and presumably McMath's) faith and religious convictions be addressed in this case? Should medical advice be given priority over religious convictions in this case, or ever?

References:

- Banks, Sandy. "In Jahi McMath saga, science and religion clash." Los Angeles Times. January 4, 2013. <http://www.latimes.com/local/la-me-0104-banks-jahi-mcmath-20140104,0,5701691,full.column#axzz2pY1MRcn8>
- L.A. Times Staff. "Jahi McMath's family: We want to help the girl, not 'play God'." Los Angeles Times. January 5, 2014. <http://www.latimes.com/local/lanow/la-me-ln-jahi-mcmaths-family-we-want-to-help-girl-not-play-god-20140105,0,3366758.story#ixzz2pYJaiVty>

CASE 3: An Affair of the Demented

Mrs. O'Brien, 75 years old, is a widow of 10 years and is diagnosed as being mildly demented. Mr. Jackson, 73 years old, is a widower of 12 years and is mild-to-moderately demented. Both are residents of a nursing home. Mr. Jackson has been in the facility for 5 years; Mrs. O'Brien moved in just five months ago.

Shortly after her arrival, Mr. Jackson and Mrs. O'Brien struck up a friendship. That friendship soon progressed into a sexual relationship. Mr. Jackson frequently accompanies Mrs. O'Brien around the facility—to meals, to the day room, etc.--and frequently wants to spend the night with her. They relate to one another the way they related to their marriage partners, with Mr. Jackson taking the lead, guiding Mrs. O'Brien around, and “taking care” of her in ways that are somewhat overbearing. Mrs. O'Brien, however, accepts and even welcomes the attention and care, especially since her marriage followed the same pattern.

He is under the impression that she is his deceased wife. Mrs. O'Brien, however, recognizes that he is not her husband, but she nevertheless welcomes the relationship and gets somewhat agitated when staff removes Mr. Jackson from her room.

Mr. Jackson's two children are accepting, even pleased, with their father's newfound relationship. Mrs. O'Brien's two children, however, are appalled and are complaining to the nursing home about how their mother is being abused and that the nursing home is not providing proper care. They are also upset that the staff is letting their mother engage in a relationship with Mr. Jackson that, in their opinion, she would never normally consent to. As they put it, “Our mother was always faithful to our father, and would never be with another man.” A couple of the staff members who provide care for Mrs. O'Brien are also opposed to the relationship. They complain that Mr. Jackson gets in their way, and that the mornings after he has spent the night, Mrs. O'Brien's dementia is exacerbated by the decreased sleep. On the other hand, some staff members find that the relationship has a positive effect on these residents, and that trying to keep them apart requires a Herculean effort that only results in agitation and upset.

Questions:

1. Should the staff actively try to keep Mrs. O'Brien and Mr. Jackson apart? Why or why not?
2. In nursing home situations, families of residents may not often have time to visit, or may not live close enough to visit regularly. Is it thus morally acceptable for family members to dictate the terms of their loved one's relationships within the nursing home, if those family members are not active participants in their loved ones' lives?
3. What ethical considerations should loom large in determining what to do in the case of this couple?

CASE 4: What is Dr. Watson?

The hospital hiring committee was suitably impressed. In preparation for the interview today, Dr. Watson had memorized all of the patient medical charts in the hospital as well as every medical journal article written in the past 20 years. As the interview came to a close, the IBM representative, speaking on behalf of Dr. Watson, made her final pitch,

“The ‘Watson’ supercomputer technology is the world’s most advanced natural language processing machine, as we all saw on the Jeopardy quiz show in 2011. Having managed to beat some of the most successful human contestants in Jeopardy history, we are now applying ‘Watson’ to bigger and more important problems, such as the diagnosis and treatment of medical disease, and we want to partner with the Metropolis Memorial Cancer Center to begin that work. ‘Dr. Watson’ as we call this health care oriented version of our supercomputer technology (otherwise known as ‘Watson’) will quite simply revolutionize your diagnostic abilities here at Metropolis Memorial Cancer Center.¹ The amount of information that doctors need to process and remember today in order to effectively diagnose and develop suitable treatment plans is simply staggering. There are patient medical charts, patient preferences, family histories, diagnostic test results, and new medical journal articles with the latest research on diseases and treatments being published every month, in addition to all of the information about human anatomy, diseases, treatments, and drug interactions that doctors learned in medical school and clinical residency. Human doctors cannot keep all of the relevant information in view during diagnosis and development of a treatment plan. But ‘Dr. Watson’ can.

Once implemented in the clinical setting, doctors will be able to ask the system to determine the most likely diagnosis for a set of symptoms that a particular patient displays. ‘Dr. Watson’ will then be able to search patient data, a patient’s treatment preferences, diagnostic test results, treatment guidelines, doctors’ and nurses’ electronic notes, clinical study information, textbooks, and journal articles to develop hypotheses that it tests and assigns scores to that indicate confidence in the accuracy of the diagnoses along with an accompanying treatment plan based on the most up to date research. Even more, ‘Dr. Watson’ can process 200 million digital pages and provide an answer to a doctor’s query in three seconds.² Fortunately, there is no need to install actual computer servers at the hospital, and instead all of Watson’s health care diagnostic and treatment capabilities can be accessed remotely by authorized users via the Internet at any suitably equipped PC or mobile computer.

With this technology in place, doctors will be able to receive the support they need in order to successfully navigate the flood of medical information they are currently faced with, and patients will benefit from expert medical diagnosis and development of a treatment plan that is assembled using the most up to date, evidence based, medical and scientific research. There is real potential here to save even more lives than our present medical system already does.

Getting right down to it, as a valuable pilot project for this technology, IBM is willing to waive any costs for utilizing this technology over the next three years in exchange for access to the data about the performance of ‘Dr. Watson’ in the clinical setting. Additionally, we will supply technical support over that time period to implement and maintain the system in the hospital.”

¹ “Dr. Watson” is a fictitious name assigned to this otherwise real medical application of the Watson supercomputer technology.

² “Memorial Sloan Kettering and IBM Watson Infographic.” Accessed on Sept. 30, 2013.
http://www.flickr.com/photos/ibm_media/7006882785/

After the IBM representative left, the committee was abuzz about the exciting prospects for this technology in the hospital. Debate quickly ensued, though, about the ethics of implementing this kind of technology in a medical setting and how it should be implemented if they decided to proceed forward with the partnership with IBM.

Questions:

1. If the “Dr. Watson” supercomputer technology is successfully implemented in the hospital and demonstrates a diagnostic/treatment plan success rate better than any other doctor in the hospital, should all doctors working at the hospital be required to submit diagnostic queries about each and all of their patients to the “Dr. Watson” system? Why or why not?
2. Suppose that the hospital required all its doctors to submit queries for each and all of their patients to the “Dr. Watson” system (which had demonstrated a diagnostic/treatment plan success rate greater than any other doctor in the hospital). Should a doctor then be allowed to refuse a diagnosis that the “Dr. Watson” system has determined to be highly likely if he thinks the diagnosis is wrong? Should a hospital-employed doctor be allowed to refuse a “Dr. Watson” recommended treatment plan or part of a treatment plan if she thinks it is wrong?
3. Given that the “Dr. Watson” system has been offered to the hospital as a free-to-use service for the next three years along with technical support, are there any compelling reason(s) nonetheless to refuse the technology? What are they? Can any of these concerns be overcome by addressing how the technology is set up in a health care setting or the rules and procedures that are designed to shape how the technology is utilized? How so?

CASE 5: New York City Soda Ban

About one-third of Americans are obese, and about 10% of US healthcare costs are tied to obesity-related disease, according to the Organisation for Economic Co-operation and Development. New York has become a national pacesetter for passing laws aimed at curbing obesity. The city was among the first to require chain restaurants to post calorie counts prominently on their menus. In 2012 New York City's Board of Health approved Mayor Michael Bloomberg's ban on large, sugar-sweetened drinks. Under the plan, all restaurants, fast-food joints, delis, movie theaters, sports stadiums and even food carts would be barred from selling sugar-sweetened drinks in cups larger than 16 ounces. The limits did not apply to drinks sold in grocery stores, diet sodas, drinks that are more than 70-percent fruit juice, or that contain alcohol. Restaurants that violate the law face a \$200 fine.

Health Commissioner Thomas Farley called the measure "a historic step to address a major health problem of our time." The plan, which requires no other authorization than the Board of Health's vote, has elicited outrage from many, including representatives of the beverage industry which launched an aggressive million-dollar lobbying campaign against the restrictions, accusing Bloomberg of running a nanny state.

One resident of the city, Mark O'Neil, argued that these restrictions represent a dangerous intrusion by the government into the personal health choices of citizens. He said, "The government should not be controlling my personal life. This is America, and I should be free to drink soda and as much of it as I want." He also worried that this was setting precedent for the government to implement more restrictive health measures. "If we let them get away with this, next they'll be looking to restrict what kind of food we can eat. Are they going to force us to exercise, too? This whole way of thinking is downright totalitarian."

"We've heard these claims of pending apocalypse before when we proposed bold public health initiatives, and they have been proven false," Samantha Levine, a Bloomberg spokeswoman, said in a statement. Though Bloomberg went ahead with the initiative and the Board of Health voted to pass it, it was quickly struck down, so the claims in this case never got the chance to be proven true or false.

"Since New York City's groundbreaking limit on the portion size of sugary beverages was prevented from going into effect on March 12, more than 2,000 New Yorkers have died from the effects of diabetes," Bloomberg said, in a statement, in defense of his previous decision. "Also during that time, the American Medical Association determined that obesity is a disease, and the New England Journal of Medicine released a study showing the deadly, and irreversible, health impacts of obesity and Type 2 diabetes — both of which are disproportionately linked to sugary drink consumption."³

Questions:

1. Many public health initiatives require some kind of restriction of personal freedoms. Is this case analogous to other public health initiatives in this respect? Why or why not?

³ <http://www.politico.com/story/2013/07/new-york-city-soda-ban-appeals-court-94916.html>

2. Does Bloomberg have a good defense for his decision? Is there anything morally problematic about it?

3. Is the so-called “soda ban” an action characteristic of a nanny state? Is running a nanny state morally problematic?

CASE 6: Physician-Enforced Vaccinations

Dr. K is a pediatrician with a busy practice in midtown Manhattan. Over the last decade or so, he's noticed more and more parents refusing to have their children immunized at routine office visits. Some say immunizations cause autism, and although he patiently explains that there is absolutely no good evidence for this claim, the parents still refuse, "just to be on the safe side."

Other parents say they can rely on herd immunity to keep their children healthy. And since most of these children go to private schools when they are old enough, immunization is not a condition for enrollment, as it is for public schools. One of Dr. K's patients goes to a private school where many parents opt-out of vaccinating their kids. Dr. K recommended that this patient's parents have their daughter fully immunized, but her mother told the doctor that she didn't think all diseases needed to be eliminated through vaccines administered in childhood. She told the doctor that if her daughter did contract one of those diseases she could just build her immune system naturally.

Dr. K is at his wit's end. He worries that non-vaccinated kids will pick up whooping cough or measles in his waiting room, which is crowded with sick children whose coughs and sneezes spread diseases very efficiently. He feels that by taking a stand against the refusal to immunize children he is fulfilling his duty as a medical professional to preserve and protect the health of his patients.

He is thinking about a new office policy: He will turn away from his practice any child that has not been vaccinated in concordance with the recommendations of the CDC's Advisory Committee on Immunization Practices. Parents who refuse to have their children immunized must find another doctor. He knows public schools require immunization for admission, and he has heard that some hospitals now require all staff to be vaccinated for the flu, so he reasons that it shouldn't be so controversial to require his patients to be immunized. After all, he isn't the only pediatrician in the city.

Nurse M, who works with Dr. K, understands Dr. K's concern but she is worried that many parents will only become angry and seek medical attention elsewhere. "Dr. K can be so hard-headed, and I worry that we might lose more patients than he realizes," she said. Nurse M is concerned that the loss of patients might mean a loss of work for her and her co-workers, but she also thinks the doctor's plan won't be effective. "Parents aren't going to immunize their kids just because he says this office requires it," she claims. "He really should be more understanding and consider that some of these families are opting out for religious reasons or because they also use alternative medicine."

Questions:

1. Would a government mandate that *all* children must be vaccinated be ethically justified, given concerns about declining vaccination rates and the return of diseases like measles?

2. Are parents who opt out of immunization, or who only agree to partial immunization, harming or helping their children? What effect, if any, might this have on their community?

3. Should Dr. K respect the wishes of his patients to control their medical care? Is he overstepping his professional bounds by taking a stand on this issue?

CASE 7: Harry's LVAD

"You said it would let me lead a more active life," gasped Harry Vu, "but I'm so tired I can't do anything except sleep. I'm so weak I can't even go to the bathroom by myself and I hurt all the time. And now you tell me I can't get any better?" Harry is 67 years old and had a left ventricle assist device implanted in his heart several weeks prior.

Dr. Smith smiled a sad little smile and shook his head. "I'm terribly sorry, Harry. Your heart just can't pump enough blood into your body, even with your LVAD's help. I'd hoped that by now you'd show distinct signs of improvement, but here we are, and this is what we've got. I'm afraid there's nothing more we can do."

Harry was silent for a few moments, eyeing Dr. Smith thoughtfully. Then he said, "You can turn off my LVAD."

"No, Harry. If I did that, you'd be dead within a couple of hours."

"I know. But I've been thinking about it, and I just—I don't want any more treatment. I want you to admit me to the hospital so you can turn the thing off. This is—" he blinked hard. "Well, I told my wife this is no life at all anymore."

"No, you don't understand," Dr. Smith was eager to explain. "Once you left the hospital, the LVAD stopped being a medical treatment and became, in effect, a part of you, much like a transplanted organ would be, or even a natural one. Just think about that for a minute. We wouldn't remove your biological heart simply because you didn't want to go on. And it would be the same thing if we disabled your LVAD."

Harry became despondent and hinted that he wanted to consult another doctor.

Questions:

1. How would you advise Harry in this case?
2. There is a biological difference between Harry's heart before he had an LVAD placed and after, so why is there no ethical difference between turning off his LVAD and removing his own heart (as the doctor seems to believe)? Or is the doctor wrong?
3. It seems as if Harry did not grasp that 1) there was a possibility this procedure might not produce its intended results, namely of allowing him to return to a more active life, and 2) that this procedure was irreversible. Who is responsible for making sure that Harry understands these aspects of this medical procedure? If Harry didn't grasp 1 or 2, then is Dr. Smith guilty of some professional or ethical misconduct?

CASE 8: The New War on Aging

Even as global life expectancy continues to climb, many on the forefront of biomedical technology research are still not satisfied with the current numbers. One company, Calico (short for California Life Company), aims to take a new focus on health care for the aging by tackling death and the aging process head-on. The company, owned and founded by Google, is in its fledgling stages and hasn't indicated what its specific research strategies or products will be, but Google CEO, Larry Page, has made it clear that he is not looking to continue in the vein of traditional approaches to health care for the aging. Rather than focus on diseases and other contributors to lower quality of life in old age, Calico wants to focus on extending the human life span and enabling a more active life for humans until their time comes.

Google engineering director and futurist, Ray Kurzweil believes that his work on computer technology is a step toward realizing a nanotechnology revolution. Kurzweil is vocal about his own efforts to prolong his life long enough to benefit from life-extending biotechnologies that he believes we will see in the next ten to twenty years.

“You and I are walking around with outdated software running in our bodies, which evolved in a very different era,” Kurzweil said. “We each have a fat insulin receptor gene that says, ‘Hold on to every calorie.’ That was a very good idea 10,000 years ago, when you worked all day to get a few calories; there were no refrigerators, so you stored them in your fat cells. I would like to tell my fat insulin receptor gene, ‘You don’t need to do that anymore.’”

Kurzweil is not just dreaming up possibilities. A lab mice experiment at the Joslin Diabetes Center, was actually able to switch off the fat insulin receptor gene in mice. These mice would eat yet stay slim. They weren't susceptible to diabetes or heart disease and lived 20% longer. Kurzweil has predicted that by the 2020's humans will be able to eat as much junk food as they like because nanotechnology will supplement their nutritional needs and control fat storage.

Ethicist Daniel Callahan is not so optimistic about Calico's mission. In a NY Times op-ed piece, he wonders if Calico has sufficiently considered the implications of these kinds of technological and medical advances.

“The fundamental difficulty here is that we cannot proceed in the usual way with this medical research, taking small steps, seeing the results and then, if they are positive, moving further,” Callahan said. “It will take decades for the changes in length of life to play out to allow assessment of their benefits and harms. By then it may be too late to reverse the damage. One likelihood, even in just a few years, is that older people who stay longer in the work force, as many are now forced to do, will close out opportunities for younger workers coming in.”

Questions:

1. If Calico succeeds in developing products that radically extend the lives of human beings, are there any legitimate moral or social concerns that suggest we shouldn't be seeking longer life spans? If there are no such concerns, what are the advantages of extending the human life span?

2. If medical companies, like Calico, seek not merely to alleviate the effects of illness and aging but to supplement and enhance the genomic structure of human beings, does this somehow go beyond the realm of medicine and commit us to transhumanism? Does a commitment to transhumanism cause any moral problems for traditional medical practice?

3. Roughly 80% of medical expenditures in the US are the result of caring for 10% of the population, largely the elderly. Should this economic reality raise any ethical concerns for future developments at Calico?

References:

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CASE 9: Mr. Dale and the World Wide Web

Whitney Sumner, the social worker for the neuro-ICU stops you in the hospital's main floor hall, saying, "Do you have a second? I was meaning to call you about a situation we've got upstairs." You say sure and while you both move to the side and corner of the hallway, as out of the way as possible, she launches into it:

The patient on the floor is Mr. Eric Dale, a 23 year old who was brought in by ambulance after he was hit by a car while riding his bicycle. Mr. Dale had been riding across the crosswalk, obeying the walk signal, when a vehicle whipped around the corner and hit him, and then sped off. He had significant head injuries, as well as major lacerations on arms and legs – according to witnesses and the police, he was thrown several yards, and in fact, into another car waiting at the light. In the early hours after his collision, he had an emergency craniotomy to reduce swelling in his brain, and that was just the beginning of his already long and continuously tenuous hospital course. Mr. Dale's prognosis remains uncertain – the injuries are severe, but, as the neurologists and neurosurgeons keep pointing out to the team and family, Mr. Dale is young and "watch and wait" is the best strategy.

Ms. Sumner leans in a bit closer at this point and lowers her voice. "The thing is, we know this is a watch and wait case – I mean, young brains recover sometimes. And he's already showing some spontaneous movements and tracking with his eyes. And everyone's rooting for him. It's not that. The thing that's bugging everyone is the website and fundraising thing. So, Mr. Dale lives out here with his brother who's a few years older – like 25 or something – but the rest of the family is all back in East – and there's a ton of kids, siblings – these two are the oldest. Mom and dad are out here and have been since the first days, with a big extended family and church community taking care of the younger kids – and they all talk daily and Skype and all that. Dad's heading back at the end of this week, I think. But, anyway, the older brother, Jim, has started a blog to keep everyone updated – and linked it to some website for donations, and the whole thing is making some people really upset. On the one hand, folks are upset for Mr. Dale – Jim is sharing all kinds of health information – I mean HIPAA protected stuff! – online. And I know the updates are important for folks back east, but they don't seem to understand that once that's out there, it's out there – Mr. Dale's got a traumatic brain injury! That can affect jobs, relationships, insurance... Our intensivist and NP tried to talk to them about it last week, but neither Jim nor the parents seem to think it's a big deal. They say he wouldn't mind – he shared everything and he'd want folks to know."

Ms. Sumner takes a deep breath and goes on: "Other folks in our unit aren't as concerned about the information – they think it's sketchy to be doing that kind of fund-raising online – they overhear the family talking about how many thousands of dollars have been donated and, well, some people have mentioned that it seems like profiting from his tragedy... but most folks here know it's ok, I mean, people do it all the time now, right? And medical bills are expensive. I don't know. Anyway, there's all that, but what bugs me most is the commentary. One of the nurses went to the website and it turns out Jim is writing not only about Mr. Dale's medical condition, but about the staff – evaluating which nurses and doctors he thinks are better or smarter, but also commenting on looks and writing things like "Eric, you'd better wake up soon

so you can meet some of these nurses. The one here today, Julie, is just your type – gorgeous and really cool...I might ask her out myself if you don't get up and get working on it.” It's nothing crude, really, but still... Even me, my name is in there too – I mean, not last names or anything, but still, it's making everyone uncomfortable. But after the last conversation about the blog – apparently the family got touchy and defensive – no one seems to want to raise the issue again – I mean, this is tough for the family. I just don't know. What do you think? What are we supposed to do about this? Is this some kind of HIPAA violation? Don't we have some kind of privacy protection as staff?”

Questions:

1. The Dale family seems to be dismissing the potential negative effects of publicly disclosing Eric's medical health information for the sake of raising financial and emotional support. Is this reasoning ethically justifiable?
2. Regardless of the legality, is the Dale family doing anything unethical by including hospital “commentary” on their blog?
3. Is it unethical for the Dale family to raise more money than is required to pay for Eric's hospital bills, whether they pocket the money or give it to Eric (should he survive)?

CASE 10: Ms. Blake Refuses the Trache

Mr. Travis Keller, social worker with the lung transplant service, calls late on a Monday afternoon with a request for ethics consultation. He's uncertain as to what he's supposed to ask in the request, as the lung transplant team doesn't often call for ethics consultations. He starts by explaining that the attending on service wanted an ethics consultant to participate in a family meeting they were planning, regarding a transplant patient who was now refusing interventions the team felt would be beneficial, that were necessary, in fact, for her recovery and rehabilitation.

Mr. Keller begins telling you about the patient, Marjorie Blake, a 47-year-old woman with pulmonary fibrosis secondary to lupus, who underwent a bilateral lung transplant 10 days ago. The transplant was successful and her "new" lungs are working well, but Ms. Blake suffered the relatively rare complication of a post-surgery stroke, followed by an upper extremity DVT the next week, and so now, 10 days later, she remains bed-bound, on the ventilator. Ms. Blake was scheduled for a tracheostomy on the previous Friday, but after initially agreeing, she refused to sign the consent, asking that the procedure be rescheduled for Monday, today. The lung transplant team is concerned because, as of this morning, Ms. Blake still refuses to consent for placement of the trache, despite the team's explanations that the procedure is necessary so she can get up and out of bed, can participate in physical therapy and rehabilitation, and exercise her transplanted lungs. In addition to the ongoing efforts of the care team to convince her to accept the trache, Ms. Blake's several siblings have been trying to talk with her, including an older sister, Raquel, who helped care for her before the transplant and who is her surrogate decision-maker.

Through multiple conversations over the weekend and into Monday, Ms. Blake's refusal has been clear, even though the reasons for that refusal are not. Ms. Blake is able to nod and shake her head, and even write (somewhat legibly), but she has not been able, or perhaps willing, to articulate why she's refusing. She appears depressed and angry, and has expressed her fear that something else will go wrong, and emphatically wrote, "I am in control." After a while, when people continue to ask her why she won't accept the trache, she closes her eyes and refuses to communicate. Her sister, Raquel, both wants to respect Ms. Blake's wishes and wants her to undergo the trache, and so Raquel is desperately trying to convince Ms. Blake to "make the smart choice" and "not to let those strong new lungs that some family donated go to waste."

Mr. Keller also tells you that the lung transplant team is really distressed: "This has been so hard – I mean, what awful luck to have the stroke, and then to have Ms. Blake refusing the trache? None of our patients do that – by the time they get the transplant, they've come so far and been through so much, they don't mind about a little incision in the neck. It just doesn't make sense. She says she hasn't given up, doesn't want to die, but she won't consent. What if she's giving up?" Mr. Keller reports that the lung transplant attending, Dr. Adam Heath, is frustrated and concerned that Ms. Blake "is not making a rational decision" and that she doesn't understand that she will likely die without the trache. He requested a psychiatric evaluation to determine if the patient has capacity for medical decision-making. According to Mr. Keller, Dr. Heath also told the team and Raquel that if Ms. Blake doesn't have capacity, he'll be the one to make the decision to do the trache "on the basis of medical necessity," which made both Mr. Keller, and Raquel, as Ms. Blake's surrogate, uncomfortable. Further, Mr. Keller tells you that he's upset

because he overheard Ms. Blake's nurse, Sue Morrow, and the charge nurse, Jenny Scott, talking about how the transplant attending is only pushing the trache because he's worried about the numbers for his transplant program if Ms. Blake dies from a complication in the first 30 days. He complains, "They don't get it. They think it's all about the numbers, because they don't see how long we take care of our transplant patients."

Questions:

1. How would you, as the clinical ethics consultant, identify and address the multiple moral concerns raised in Mr. Keller's request for ethics consultation?
2. Several people in this case, including Ms. Blake herself, might claim to have Ms. Blake's best interest in mind, but do any of them actually have her best interest in mind? What immediate actions would be in her best interest?
3. Does it matter if Dr. Heath only cares about Ms. Blake's survival because he's worried about the numbers for his transplant program? Is it ethically better if he cares about Ms. Blake's survival for her sake or her family's sake? Why?