

PICU Prometheus: Ethical issues in the treatment of very sick children in Paediatric Intensive Care

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Abstract

Through a focus on one child's extended stay in a Pediatric Intensive Care Unit, I raise four general questions about pediatric medicine: How should physicians communicate with parents of very sick children? How should physicians involve parents of very sick children in treatment decisions? How should care be coordinated when a child is being treated by different medical teams with rotating personnel? Should the guidelines for making judgments of medical futility and discontinuation of treatment differ when the patient is a child rather than an adult?

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The Pediatric Intensive Care Unit—or PICU—is on the tenth floor of the Children's Hospital, at the top.¹ The facility has 11 beds. Eight of the beds are situated in a single large rectangular room. When privacy is required, nurses pull the curtains closed. But most of the time the curtains are open and the patients can see and be seen.

The remaining three beds are more private, more isolated. Each of them is in a room by itself with a smaller buffer room before it. These rooms are reserved for patients who are infectious or whose immune systems are not functioning properly. Before entering these rooms, one must wash one's hands and put on a gown and gloves. Upon leaving, one must discard the gown and gloves and wash again. This is what the buffer rooms are for: to ensure adherence to these heightened hygienic procedures.

One of these three rooms is especially isolated. The other two offer direct lines of sight from the beds through the buffer rooms to the main PICU area. But the third room is at the corner of the facility. From the bed of this room, the rest of the PICU cannot be seen.

In the bed lies 8-year-old Billy Strawson. Billy has been in the hospital for 4½ months. He's been in the corner room of the PICU for 4 months of that time.

Billy comes from a small town several hours away. His mother, Miss Strawson, has quit her job and moved into temporary accommodations in the city (Billy's father is not in the picture). She comes to the PICU every day. She enters the buffer room, washes her hands, and puts on a gown and gloves. Then she sits in a chair and gazes alternately at the bed and out the window.

The doctors in the PICU think Billy is going to die. The nurses in the PICU think Billy's treatment is tantamount to torture. But there is no plan to withdraw life-support from Billy, and his treatment continues.

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Billy's case raises a number of questions—questions that I will explore in what follows. One is how physicians should communicate with parents of very sick children. A second question is how best to involve parents of very sick children in treatment decisions. A third question is how best to coordinate care when a child is being treated by different medical teams with rotating personnel. A fourth question is whether the guidelines for making judgments of medical futility and discontinuation of treatment should differ when the patient is a child rather than an adult. These four questions are interrelated and, in the account that follows, I have woven together my discussion of them. I have also chosen a more narrative form because it reflects that I do not have answers to the questions raised by Billy's case.² If nothing else, I hope my discussion encourages others—especially physicians, nurses, and parents who have spent time in pediatric intensive care units—to help provide such answers.

The high-tech multi-team medicine of contemporary PICUs saves children's lives every day of the week. It is certainly not my intention to disparage these wonderful accomplishments. But I do want to explore some of the less obvious costs of this type of medicine, and ask how these costs might be minimized.

Billy was born prematurely, weighing only 600 grams. During his ensuing stay in the Neonatal Intensive Care Unit (NICU), he became bronchodysplastic, which led to his developing severe asthma. He also contracted viral hepatitis of an unknown variety, probably from blood products delivered in the NICU. The hepatitis caused cirrhosis, which eventually led to Billy's having to undergo liver transplant surgery when he was 7 years old.

The surgeons did not close up Billy's belly after the transplant surgery because the liver was oversized and they worried that the resulting pressure on his abdominal compartment could endanger his respiratory status, which was already compromised by his asthma. But an open wound is always at great risk of infection, for the obvious reason that it lacks skin, the body's best defense against invasion. And this is why Billy was placed in the corner room of the PICU, with its special hygienic precautions.

Billy's open belly wound became infected nonetheless. It was a particularly nasty infection too, the kind the popular press a few years back dubbed "the flesh-eating bacteria". The doctors managed to defeat the infection with powerful antibiotics, but not before it had eaten away so much of the flesh around the wound that there was no longer enough viable tissue to suture. At the same time, Billy's spleen became extremely enlarged, probably as a result of decreased blood supply due to a poorly functioning portal vein. This caused Billy's open belly to balloon to the size of a basketball, further dimming the prospects of closure. Billy's skin acquired the orange hue of a basketball as well, the effect of biliary dysfunction that caused his bilirubin count to climb to 40. He developed a bowel obstruction that prevented him from absorbing adequate nutrition. He became extremely hypertensive. His kidneys began to shut down.

Billy was initially put on a ventilator and eventually given a tracheostomy. He was given a gastrointestinal tube for nutrition and catheters for urination and dialysis access. He had permanent lines placed to draw blood and supply medication.

Thus, by his fifth month in the hospital, Billy has sprouted a veritable bouquet of life-sustaining tubes. Every morning, the tubes' locations are checked by X-ray, and about once a week one of them has to be surgically adjusted. Their flow is carefully regulated all day long.

The nurse assigned to Billy on any given shift usually has no time left over for other patients. Seeing to Billy is a full time job—or perhaps four full-time jobs, when you consider that the care has to be given 24 hours a day, 7 days a week.

The most difficult part of the nurse's job is tending to Billy's wounds. For now, in his fifth month in the hospital, Billy has two wounds: the one on his belly, from the initial transplant

surgery, and a new one on his backside, where the skin has broken down from poor nutrition and the constant pressure of lying in bed. Each of these must be dressed twice a day.

The old wound is dealt with first. It is the shape of an American football and stretches from one side of Billy's torso to the other. The wound is covered by a copious amount of bandage and tape, all of which must be peeled off at each re-dressing. The flesh underneath is red and angry and marked by several oozing brown pustules. At times during Billy's hospital stay, parts of the wound have not had any flesh at all—just naked viscera, liver, and spleen plainly exposed. Onto this wound, every day and every night, bandages are placed and then, with tape, pressed down.

The new wound is dealt with next. This requires two nurses, one to roll Billy halfway over and hold him on his side, the other to do the dressing. The wound is the size of a silver dollar and burrows straight down to the coccyx bone, which is visible. The flesh surrounding the hole is inflamed. The nurse packs the open area with bandages, tapes it up as delicately as she can, then lays Billy back down on it, where he will remain until the next redressing 12 hours later.

Billy was never what you would call a cooperative patient. He battled the doctors and nurses from the start. There was even a sign on his door that said that he did not like his forehead to be stroked and did not like to be called "Sweetie" or "Honey". His mother said he was "a fighter". The doctors and nurses said he was "one mean little kid", but they always said it admiringly. He had every reason to be mean, and defiance was just about the only way he had of exercising his will.

During his fourth month in the hospital, however, Billy's spirits turned away from angry to what the staff called superagitated. Instead of squirming only to avoid prods and pricks, he now began to thrash about all day long. He slept little, and when he did it was fitful. Twice each day, when his wounds were re-dressed, he scrunched his eyes shut and bared his teeth in a grimace, his breath coming in jagged irregular bursts.

Most conspicuous of all during this period were Billy's eyes. They were wide open and wild, darting desperately from person to person as one member of the medical team and then another bent down to examine him. These were not the eyes of a fighter or a mean little kid. They were the eyes of a terrified creature—of a being in uncomprehending fear. Many who saw him said exactly the same thing: "He's got the look of a deer caught in the headlights". It's a shame this expression has become so figurative and cliché, as it makes it harder to appreciate fully its aptness in describing Billy at this stage.

The PICU physicians responded to Billy's superagitation by administering larger doses of sedatives and painkillers. When that did not work, they added different kinds of sedatives and painkillers. When that did not work, they raised the dosages of the various drugs even higher. Still, it did not work. Indeed, Billy became even more frantic than before and slept even less. The PICU physicians wondered if he was suffering a "paradoxical effect" of the sedatives and painkillers, when a drug does for one person the opposite of what it does for most. They also wondered whether Billy was suffering from ICU psychosis, a surprisingly literal description of the mental symptoms some people exhibit during an extended stay in intensive care. They decided to wean Billy off some of the sedatives and painkillers, bring in new ones, and add Haldol, a powerful anti-psychotic.

This new combination of drugs seemed to work. Billy calmed down. Unfortunately, he calmed down too much, sinking into a deep, non-responsive stupor. His eyes were three-quarters shut and wouldn't track a moving finger. He did not acknowledge questions or comments in any way. The only time he showed any life was when his wounds were redressed, when he still gasped and grimaced. "He won't even look at you", one of the

nurses said to me. Then she added, “Well, he looks at you, but it’s like you’re not there. Like he’s not there. He’s totally out of it, totally withdrawn. There’s nothing there but a glazed blank stare”.

The PICU physicians responded to this troubling stupor by pulling back on Billy’s medications—first a little, then a lot. Eventually, by the beginning of his fifth month in the hospital, Billy is at medication levels that are exceedingly low, especially for someone who has built up such an enormous tolerance over the previous months. This level of drugs alone should have very little if any effect on Billy’s mental status. Still there is no change. Except for the two times each day when his wounds are re-dressed, Billy remains virtually inert in his PICU bed.

Who is coordinating Billy’s treatment? Who has overseen the decisions that have brought him to this point, and who will oversee the decisions that determine where he goes from here?

Not Billy himself. Early on in his treatment, efforts were made to give Billy as much information as he could understand about what he was going to have to face (and, even then, Billy often expressed hostility, suggesting that, if he had had the choice, he would have refused many of the procedures that were performed). But by the time the very difficult decisions arise, Billy’s mental state has deteriorated past the point at which he can engage in meaningful discussion about the treatment options.

Those who are officially given the power to decide in pediatric cases such as Billy’s are the parents. It’s the parents who sign the admission papers and it’s the parents who are presented with the informed consent forms.³ My observations suggest, however, that some parents exercise far less decision-making power than the official picture would lead us to expect. I have consistently observed physicians take great care to help parents understand what is going to happen. But the thoughts and feelings of some parents I’ve observed have been largely epiphenomenal—determined by their child’s treatment, not determiners of it.

Parents’ lack of causally efficacious involvement in decision-making can be partly chalked up to factors general to the practice of hospital medicine as a whole. But there are also factors unique to pediatric critical care that help account for the bystander role that some parents play.

For one thing, some physicians I’ve observed seem less willing to allow a parent to make what they perceive to be the wrong choice than to allow an adult patient to make such a choice for himself. An adult who insists on a course of treatment (or, more accurately, nontreatment) that physicians deem unwise will almost always be given his own way. If he makes a big mistake, well, he’s the one who will have to pay for it. But in pediatrics, the person who might insist on an unwise course (the parent) is different from the patient who will directly endure the results. And the physicians’ primary duty is to the patient. So in order to forestall the possibility of counterproductive inference, some physicians may be more likely to keep parents out of the loop.

Some physicians I have observed also seem to think that parents of very sick children are emotionally ill-equipped to take part in medical decision-making that continually trying to involve them in the process is an unnecessary imposition. According to this way of thinking, hashing out difficult decision-making details behind closed doors does parents a favor, allowing them to concentrate on personal matters without burdening them with medical issues they are in no condition to handle.

This approach can be especially pronounced in pediatrics when the decisions are truly life or death. To see this, consider the contrasting case of a gravely ill adult, for example a 75-year-old male patient. Without any treatment, let us say, the patient will die in 6 months. With treatment, he has a 10% chance of surviving another 5 to 10 years. But the treatment involved is extremely unpleasant and debilitating, and if it does not succeed (and there is a

90% chance it won't), the patient will have spent all of his remaining time in great distress in a hospital room.

Should this patient take the treatment? It depends on the patient's values, on what's important to him and his attitude toward risk. But it's certainly possible that he will reasonably decide that the low chance of gaining a few more years is not worth the high chance of suffering torturous medical ministrations continually until he dies.

Now imagine that the patient is 8 years old, and that the decision is in the hands of his parents. Could they decide not to give the child a chance at 5 or 10 more years? What if the chances of survival are only 5%, but the length of survival is 10 or 20 years? Could the parents decide that these odds are too low and thus forgo the treatment, knowing that this will lead to the child's death in a matter of months?

Many parents I've observed seem not to be able to make the decision to forgo treatment in such cases. When offered a chance that their child may recover, these parents seem compelled to take it. And they seem to find the offer just as difficult to refuse even as the chances of survival fall and the consequences of treatment worsen.

What many parents I've observed seem to need before they can fully address the possibility of discontinuing treatment is an unambiguous medical statement of futility. They need the doctors to say that, in their professional opinion, continued treatment is not medically indicated. Once this statement has been made, allowing the child to die is no longer a judgment-call based in part on the value a parent places on her child's life. The expertise of medical science has eliminated the burden of judgment. As one PICU doctor put it, "I don't want to leave it in the hands of the parents. I want to tell them it's not medically indicated".

What this approach can obscure, however, is that statements about what is medically indicated can themselves be judgment-calls. Only it then becomes the physician who is making the judgment, not the patient or the family.

There are, it is true, some cases in which a determination of futility is clear and incontrovertible (for instance, when a patient is brain-dead or anencephalic). But, in many pediatric cases, physicians cannot say with absolute certainty that continued treatment will fail to produce any benefit. And the possibility of recovery, no matter how small, places the question of what to recommend to parents back in the realm of values, of weighing the low chance of recovery against the high costs of treatment.

What judgments do pediatric physicians make in these circumstances? How do they weigh possibility of benefit against certainty of cost? My observations suggest that a significant percentage of pediatric physicians end up coming to pretty much the same conclusion that parents feel compelled to endorse when left to their own devices: that even a very small possibility of benefit outweighs the certainty of great distress. When the patient is a child with any hope of recovery, some physicians are almost as unlikely to raise the idea of discontinuation of treatment as parents are to bring it up on their own.

Consider Billy. There remains at least a bare physical possibility that he will survive. And while that bare physical possibility would not have deterred the doctors from putting on the table the option of discontinuing treatment for a 75-year-old man, it does deter them from putting that option on the table for Billy. And given that the doctors do not raise this option, it is no surprise that Miss Strawson does not bring it up.

When I asked one of the PICU doctors about his reluctance to suggest discontinuation of treatment, he said to me: "Our perspective may seem to be a little warped here. But we've had some kids we thought would never make it, then 6 months later they're knocking on our door". This statement was echoed by several other physicians, each of whom had a story to tell of a child, initially thought to have no hope, who ended up completing a near-total recovery.

I take it that the implication we should draw from these statements is that the life of the one child who defies the odds is worth the suffering of all the other children who succumb. The possible benefits of continuing treatment outweigh the actual (not merely possible) costs.

And what are the costs? There are different kinds. There is the financial cost, which for Billy is more than \$1,200,000 in PICU bills alone, not including doctors' fees. There is the resource cost: 5 months' occupation of an especially hygienic PICU room, plus round-the-clock medical attention. There is the work cost to the staff, and the emotional cost to Miss Strawson.

There is no indication, however, that any of these things plays a role in the doctors' thinking. Now perhaps there is a good reason for this. Perhaps the doctors' special fiduciary relationship to the patient precludes consideration of costs to any third party. So what costs should the doctors take into consideration? I presume the answer is, those borne by the patient himself. And this means, in Billy's case, the cost of bearing whatever it is that drove him first to superagitated heights and then to stuporous depths.

Does the small chance of benefit outweigh this cost to Billy? During Billy's first 5 months in the hospital, the question was never seriously addressed. And this suggests that the suffering of young children may sometimes not be given the same kind of weight in treatment decisions as is given to the suffering of older adults. That is not to say that doctors and parents don't care immensely about children's suffering; of course they do. But the zeal to give children a shot at recovery can lead them to place their care about suffering to one side when making life and death decisions.

Let us now turn to a different aspect of Billy's case, and that is the sharp difference between the staff's conversations among themselves and their conversations with Miss Strawson. Behind closed doors the nurses and doctors shake their heads and say things like, "He's got no more than a 10% chance, if that". But in front of Miss Strawson, they give no clear indication that Billy has not got a decent chance of recovery. What explains this difference?

One point the doctors emphasize is the uncertainty of Billy's prognosis. They might think Billy is not going to make it, but they do not know for sure, and so (the doctors say) it is not appropriate for them to share their worries with Miss Strawson.

It is hard to see, however, how the existence of uncertainty can fully account for the difference between the doctors' conversations with Miss Strawson and their conversations among themselves. For physicians are almost never absolutely sure of a prognosis, but that does not keep them from giving patients' their best estimate of what is going to happen in other situations. And if a physician thinks there is a 10% chance of survival, it is still deceptive for him to say only that "it could go either way", with the 50% chance that statement implies.

Another factor underlying the difference could be the physicians' belief that sharing the full extent of their grim prognosis could do no good and may cause harm. Hearing that Billy will probably die will devastate his mother. Of course if he does die, his mother will be devastated anyway. But why bring the devastation on earlier than necessary, especially since there is still a possibility that he will survive? (the uncertainty point making another appearance here). Perhaps, moreover, a parent who thinks her child is going to die will be less able to provide the kind of hopeful love and support that can improve a child's chance of recovery.

Physicians motivated by this way of thinking might be well-intentioned. But it is worrying to think of someone else deciding what a parent needs to hear in order to provide hopeful love and support. It is also worrying to think of someone else deciding to spare a parent the

reality of a child's condition. Maybe the parent won't handle the reality well, but the opportunity to handle it is, nonetheless, what parents are owed.

This way of thinking can also create conditions that effectively beg the question against discontinuation of treatment. This point can be put in terms of materiality. According to most standards of informed consent, doctors are obligated to disclose the facts that could be material to a patient's decision-making (or, in the case of young children, the decision-making of the patient's parents). A fact is material if it could affect in one way or another what the patient decides to do. So if a fact about the condition of the patient can have no effect whatsoever on the patient's decision-making, then the doctor is not obligated to disclose it. Now in Billy's case, the doctors might think that their belief that Billy has a very low chance of recovery is immaterial, in that the course of Billy's treatment will remain the same whether or not they share this belief with Miss Strawson. All we know for sure, however, is that the low chance of recovery is immaterial to the doctors, that the doctors think that this low chance on its own does not warrant discontinuation of treatment. For Miss Strawson, is very unlikely to initiate discussion of discontinuation herself, especially as she has been given no clear indication that Billy doesn't have a decent chance of recovery.

By overestimating uncertainty and immateriality, furthermore, doctors might at times conceal from themselves a simpler reason they do not share with a patient or patient's family the full extent of a grim prognosis. That simpler reason may be that doctors do not like bearing bad news any more than the rest of us.

To have to tell a mother her son's chances of survival are less than 10% is a terrible thing. And some physicians are no more comfortable with this task than anyone else. What physicians are trained to do—and what they want to do—is make patients well. But such training does not necessarily help with the task of delivering bad news to parents. The task is also time-consuming. And physicians are always short of time. There are, as well, institutional forces that can surround a physician's reluctance to share the full prognosis with a parent. To see those forces at work, let us return to some of the details of the coordination of Billy's treatment.

The patient–physician relationship used to be an easy thing to describe. It was the sum of interactions between a patient and his or her doctor. But in today's large university hospitals, matters are not so simple. Many different physicians participate in the care of an individual patient. And many of the interactions that determine patient care occur between one physician and another, without the patient being directly involved. The patient–physician relationship can thus be diffused, if not diluted.

One feature of care in Billy's hospital that puts pressure on integrated patient–physician relationships is the rotation of medical personnel. In the PICU, for instance, the medical team consists of an attending physician, who has responsibility for a patient's overall plan of care, and two residents, who see to most of the day-to-day details. The attending physician typically stays on the PICU service for 2–4 weeks, then goes off service for a month or two while other attendings come on for their own 2–4 week shifts. The residents serve for a month and then leave for good, to be replaced by other residents who also serve for a month and then leave for good. The danger is that this shifting of personnel can cause medical issues to be stretched out instead of expeditiously resolved. We can bring this worry into focus by looking at the treatment of Billy's mental condition during his fourth and fifth months in the hospital.

Billy began his ascent to the extreme heights of agitation in the final week of May. The attending physician noticed that Billy was becoming more distressed, but he witnessed only the first 4 days of this development. This was not enough time for him to declare it a definite trend. He could not be sure that it was not merely a brief disturbance, and that Billy would

not settle back to his baseline in a day or two. He also realized that at the beginning of the next week he would pass the reins over to another attending physician, who might have a different strategy for dealing with Billy's condition. And it would be inappropriate to put the next attending in a position in which he had either to continue with a course of treatment he himself did not completely endorse or reverse a course of treatment that had only been commenced a day or two before. So the first attending physician refrained from making any significant changes to the medical plan.

When the next attending physician came on service at the beginning of June, Billy was appreciably more agitated than he had been the week before. But because the new physician had not seen Billy the previous week, he did not know how far beyond baseline Billy had come. The previous physician had noted developments in Billy's conditions on the chart, and the nurses who had been taking care of Billy made strong mention of his deteriorating state. But agitation does not admit of purely objective measurement. And the new physician felt that he could not responsibly order any major changes to Billy's treatment plan until he had assessed Billy's condition for himself. So he decided to observe Billy for a few days.

By the end of the first week of June, it had become clear to the physician that Billy's agitation was a terrible problem. He increased Billy's sedation, but this seemed to have an effect opposite to what was intended. So in the second week of the month, he brought on board the anti-psychotics and began to reduce some of the sedatives.

After the first two weeks of June, however, the second attending physician went off service and a new—a third—attending physician came on. The third physician was filling in for another, vacationing physician, so she was on for only a week. It was during this time that Billy began to sink into his deep stupor. The third physician pulled back a bit on Billy's sedatives, but did not do a lot more, since the period of time she was taking care of him was not long enough for her to formulate and see through a large-scale change in treatment plan.

The fourth week of June, the first attending physician—that is, the physician who had been on service the last week of May—came back on for a week (filling in for the still vacationing physician). When this physician had last been there, Billy was just beginning his ascent to superagitation. Now, 3 weeks later, Billy was almost entirely non-responsive. The physician thought, reasonably enough, that medication was part of the problem. So he pulled back on even more drugs than the previous physician had done during the third week of the month. But by the end of the fourth week, Billy was still almost entirely non-responsive.

The next week was the beginning of July. And now a new—a fourth—physician came on service. He was told of Billy's deteriorating mental state, but he did not feel comfortable making any major changes to Billy's treatment until he had had some time to assess Billy's condition for himself. On his first day of rounds, he wondered how "out of it" Billy really was. He followed the direction of Billy's eyes (which were three-quarters closed) and then expressed doubt about whether Billy was as non-responsive as he had been led to believe. "He seems to be watching cartoons", the physician said. To which a nurse caustically responded (but only after the physician had left the room), "That's only because they stuck the television set where his head was pointed".

Perhaps the fourth physician comes off looking bad in his initial assessment of Billy's mental condition. But he was simply doing his job, which involves checking everything for himself before making decisions that could have the gravest of consequences. When the stakes are so high, there's a limit to how much one can rely on the observation and judgment of others. Nonetheless, it's hard not to wonder whether the days lost during hand-offs from one attending physician to another allowed Billy to reach agitated heights and stuporous depths greater than he would have if care had been coordinated from a single, continuous

(and more rapidly responsive) perspective. And even if Billy's rise and fall was inexorable (and it very well might have been), it's still hard not to wish that throughout this ordeal Billy's mother had had one physician to talk with instead of a series of them. For as each physician needed a few days to get to know the condition of the patient, and as each physician was concerned not to contradict or be contradicted by any of the other physicians, Billy's mother ended up consistently hearing assessments that were notably more tentative and less pessimistic than those expressed out of her earshot.

The rotation of personnel within a single medical unit is a diachronic obstacle to continuity of care, something due to the passage of time in an extended hospital stay. But for patients with multiple medical problems there may also arise an obstacle that is synchronic, or due to the differences between medical units at any single moment in time.

Within a typical university hospital, a patient with a number of different problems will be treated by a number of different specialists, each a member of a distinct medical team from its own medical discipline. The benefits of this multi-disciplinary approach are obvious. It gives patients state-of-the-art care for each of their problems, something no single physician or team could provide. But physicians from different disciplines take different perspectives on the same patient. They focus on different indicators, concentrate on different systems. And the importance one physician places on one consideration may sit in uneasy tension with the importance another physician places on another consideration. At times, as a result, the different medical perspectives can fail to produce a singled, coordinated view of a patient's case. And while it may be difficult enough to get the rotating members of one medical team on the same page, that can look like a piece of cake compared to the challenge of trying to bring together physicians from different teams.

Over the months Billy has been in the hospital, three groups have been consistently involved in his care: the transplant team, the PICU physicians, and the PICU nurses. Billy was first admitted to the hospital for his liver operation. Transplant is thus the primary team, the ones with ultimate veto power. But Billy spends his time in the PICU, and so it is the PICU physicians who deal with most of his medical problems. Billy also needs a great deal of hour-to-hour care, and it's the nurses who provide that.

The transplant team focuses on Billy's liver function, which never falls to really terrible levels. Transplant also notes that Billy's lungs and kidneys have not become irreversibly dysfunctional. They acknowledge that each of these systems is seriously ailing but maintain that none of them has definitely declared itself unrecoverable.

The PICU physicians agree with transplant that none of Billy's individual problems on its own is incontrovertibly a terminal condition. But they attend more to the sum of Billy's problems, to what they take to be his creeping multi-organ system failure. So while transplant is impressed by the fact that nothing about Billy's condition is incompatible with recovery, PICU is impressed by the systematic breaking down of Billy's body as a whole. The two teams do not disagree about any specific, tangible feature of Billy's condition, but PICU is markedly more pessimistic than transplant.

The PICU nurses are more pessimistic than even the PICU physicians. They find it hard to imagine that Billy will ever pull out of it, and they are deeply troubled by the nature of his continuing treatment. As one of the nurses said to me, "This is torture. What we're doing to him is torture".

The differences between the assessments of the transplant team, the PICU physicians and the nurses are not simply a feature of the personal dispositions of the caregivers involved. They are organic to institutional roles. Transplant surgeons are trained to focus on the results of their transplantation, PICU physicians are trained to attend to the array of functions monitored and regulated by ICUs, and nurses are trained to provide care and

comfort for the patient as a whole. The different perspectives are supposed to cohere in a manner that gives patients the best care possible, and things do often work out that way. But the perspectives can also fragment, as they did in the third month, when the teams were trying to determine what to do about Billy's spleen.

It had become clear by the third month that Billy's spleen function was minimal to nil. Because the spleen was so enlarged, moreover, it was impossible to close up Billy's belly wound. The enlarged spleen also exerted pressure throughout Billy's abdominal compartment, which may have caused his renal dysfunction.

It seemed, then, that a splenectomy was in order. But the spleen is a very vascular organ, which makes it difficult to cut away without a great deal of bleeding. And this made the operation especially dangerous for Billy, who was hypertensive and thus especially prone to bad bleeds.

The transplant team thought the risk was too great. The surgery itself could kill Billy, they reasoned, so it would be better not to try it. Allow Billy's body to try to heal on its own, they thought.

The PICU physicians thought the risk was worth taking. A splenectomy held out the hope of significant improvement. And, as PICU saw it, the possibility that Billy might die on the operating table was outweighed by the fact that he was already suffering and going downhill fast. Something new had to be tried.

The transplant team and the PICU physicians discussed the issue over the phone and during their occasional meetings. Transplant remained convinced that surgery was a bad idea, chiefly because they didn't think Billy's current state was so dire that it warranted something so risky. PICU remained convinced that surgery was a good idea, chiefly because they thought Billy's current state was so dire. In the end, transplant, as the primary team, had final say. The splenectomy was not performed.⁴

Now it is unhelpful to speculate about whether it would have been better to perform the operation. But it is worth noting a number of things about this episode that reveal telling features about how multi-team decision-making was practiced in this case.

One point worth noting is that the way the decision was made involved a starkly inverse relationship between decision-making influence and amount of time spent with the patient. The people who spent the most time with Billy were the nurses, who were in his room attending to him for hours every day. But the nurses had no real active role in the decision about Billy's spleen.⁵ The PICU physicians spent 2–3 hours a day on Billy. They were actually in his room for about 30 minutes. The rest of the time they were in the buffer room. The PICU physicians made most of the day-to-day decisions about Billy. But large-scale treatment strategies had to be approved by the transplant team. The transplant team spent a few minutes each day in the buffer room, reading charts. They were the ones who had final say over Billy's treatment.

The events that led to Billy's not having a splenectomy also reveal how much of multi-team decision-making can take place behind closed doors. Different physicians had different ideas about what to do for Billy, and they discussed the issues amongst themselves in frank terms. But those discussions were never opened up to Miss Strawson. The teams did not explain to her their disagreement, much less present to her competing recommendations to choose between. They resolved the issue as best they could amongst themselves, and when they spoke with Miss Strawson they all stuck to the party line. The nurses, as their institutional role dictated, followed the physicians' lead.

Why were disagreements such as those surrounding the possibility of Billy's having a splenectomy handled behind the scenes? Part of the reason might have been the physicians' belief that it was better to spare Miss Strawson from agonizing over a decision she was

ill-equipped to make. Another part of the reason might have been the belief that in the event of an unfortunate outcome, regrets, recriminations and lawsuits would be more likely to follow if Miss Strawson had been privy to the controversial nature of a treatment decision. Still another part of the reason might have been the belief that to air differences would have been to violate the basic professional courtesy of not criticizing another member of staff in front of a patient or his family.

Whatever the reason, the result was that at the care committee meetings, when representatives from each unit involved with Billy's care met with Miss Strawson, all the medical personnel spoke with one voice. By the time of these meeting, the disagreements about Billy's case had been resolved, or suppressed. Far from being transparent to Miss Strawson, much of the medical decision-making in Billy's case was decidedly opaque.⁶

Pressure to stick to the party line also played a big role in shielding Miss Strawson from the grim view of Billy's chances that the PICU staff harbored. For no one wants to tell a patient's mother that the patient is probably going to die until everyone else is willing to say so as well. So all it takes is one key player (e.g., a transplant surgeon) not to sign on to a gloomy verdict to prevent all the other physicians and nurses from delivering it.

This is why I said earlier that there are institutional forces that encase the physicians' reluctance to share with Miss Strawson the full extent of their grim prognosis. The PICU physicians think Billy is going to die, but they do not want to tell Miss Strawson. And the hopeful statements of other physicians make it more comfortable for them to keep their grim predictions to themselves.

But that does not mean the PICU physicians are perfectly comfortable, either. Despite their own reluctance and despite their hands' being tied by the transplant team, several of the PICU physicians still feel a nagging concern, pressed frequently by the nurses, that they are not being completely fair to Miss Strawson. This concern was greater when Billy was ascending the heights of superagitation, but it has not entirely gone away even now, when Billy has fallen to his stuporous depths (although it has become less conspicuous). The PICU physicians do not want to share with Miss Strawson the full extent of their pessimism, but they are nonetheless uncomfortable with the idea that they are doling out unwarranted optimism. They do not want to destroy her hope, but at the same time they hope she is preparing herself for the worst. They do not want to spread gloom, but neither do they want to shed false light.

Caught between a rock and a hard place, the PICU physicians try to squeeze their way out by lubricating gravity with vagueness. Every 5 days or so, they say to Miss Strawson things such as, "It's a tough road ahead for Billy, a really tough road", and "These are very big problems for Billy, there's no way to sugarcoat it". Their tone and aspect on these occasions is always very somber, as they sit in the buffer-room looking with Miss Strawson through the window at Billy's bed. Miss Strawson nods, crying silently. Then she says, "But he's a fighter, is not he?" And the PICU physicians agree. He is a fighter.

On the basis of these interactions, the physicians choose to believe that Miss Strawson understands that Billy is unlikely to recover. "Deep inside", one physician tells me, "she knows that he's not going to make it. She understands at some level that we're approaching the final stage, the end of the journey". "She knows, she knows", intones another with a knowing closed-eye nod. "He's hanging on by a thin thread. The ball game's almost over. Ninth inning, two outs, no one on, down by four".

But the physicians' beliefs in this case presuppose rather amazing powers of intuition. They presuppose that Miss Strawson is able to intuit Billy's chance of survival from the grave but vague comments of the physicians, and they presuppose that the physicians are able to intuit Miss Strawson's beliefs from the teary nods with which she responds to those comments.

There are, moreover, some indications that Miss Strawson does not grasp the physicians' veiled meaning. For instance, one of the Miss Strawson's friends, while visiting, says to her, "He's got more scars than anyone I've ever seen". To which Miss Strawson responds, "We're going to get him home and we'll deal with the scars then". And she says this in the fifth month of Billy's hospitalization, the day after one of the somber conversations that convinced a physician that at some deep level she understood ("She knows, she knows") the unlikelihood of recovery.

The same week, Miss Strawson asks the nurse if Billy's belly wound is the worst she's ever seen. "No", says the nurse, "I've seen worse wounds than this". "And it's gotten better, has not it?", says Miss Strawson. "Yes", says the nurse, "it has". "You see", says Miss Strawson, "he's healing. Which means his nutrition must not be so bad. They say they're no miracles, but I've seen miracles right in this bed".

"I ca not give up on him", she says a few days later. "He's always been a fighter, and I do not think he's done fighting. I think he's still fighting".

So Billy continues to languish in the tenth floor corner room of the PICU. Every day, X-rays are taken and blood tests are drawn. Every day, the medical teams stop by on their rounds. Every day, nurses give Billy round-the-clock attention. And every day, Billy's mother washes thoroughly, dons gown and gloves, and sits in her chair, looking alternately at the bed and out the window.

Twice every day Billy's wounds are redressed. And each time, his lips pull back in a grimace, his eyes close tighter, and his breath quickens and breaks.

As I noted earlier, one of the PICU physicians once said to me, "Our perspective may seem to be a little warped here. But we've had some kids we thought would never make it, then 6 months later they're knocking on our door". I repeat this statement because I think it needs to be fully appreciated in order to come to a true and fair understanding of the way Billy has been treated. Some children do defy the odds. They look like they are going to die in the hospital. But then, to the amazement of everyone, they recover. They go home, they do school-work, they play with friends, and they live a life. Parent after grateful parent calls the recovery a miracle. But if it is a miracle, it is one that would not have taken place were it not for the combined expertise and special caution of high-tech multi-team hospital medicine. And it is completely understandable that a physician who has been involved in even just one of these cases thereafter places more faith in the medical process and less in his personal doubts of recovery.

High-tech multi-teamed hospital medicine does wonderful things; only the most egregious Luddite can deny this. But the wonderful things come at a price; and only most obstinate Pollyanna can deny this. To spend a few days in the tenth floor corner room of the PICU—to watch Billy as his wounds are redressed—is to grasp that price in all its palpability.

In Greek mythology, the Titan god Prometheus is credited with bestowing on mortals the gifts of handicrafts, letters, and the healing arts, as well as implanting in them a blind hope that obscured foreknowledge of death and kindled productivity. Most significant of all, Prometheus gave the gift of fire, or spark of technology, which Zeus had forbidden mortals from possessing. As punishment, Zeus chained Prometheus to a rock on the top of a mountain and sent eagles to feed on his liver. Every night, Prometheus's liver would grow back, and every day the eagles would return to devour it again.

In the Greek telling of the story, Zeus eventually freed Prometheus. But Kafka tells a different version. As Kafka tells it, Prometheus, goaded by the pain of the tearing beaks, pressed himself deeper and deeper into the rock until he became one with it. In the months that I observed Billy, I came to think of him as Promethean, in Kafka's sense: strapped in a

bed in a room high above the city, his wounds re-opened daily, sinking deeper and deeper into his stupor, paying the price of our miraculous medical technology.

In the middle of his fifth month in the hospital, Billy rather suddenly came back to life. He started moving about in bed and seemed to regain some of his fighting spirit. Tests did not show any improvement, and no one could explain his increase in activity.

Miss Strawson took this development to be the beginning of Billy's recovery. The physicians did not tell her she was wrong. But one of them said to me, "Billy's turning the corner, but he's going in a circle". Said another, "This is Billy's last gasp. I have no evidence to support it, but I think this is it for Billy. He'll improve for a short time and then totally nosedive".

And in fact that is just what happened. After 2 days of activity, Billy sank once again into his stupor. And this time his bilirubin rose even higher than before and his nutrition plummeted even lower. He was simply not absorbing enough food to stay alive.

It was decided that surgery should be performed to remove Billy's bowel obstruction. But at the first incision, Billy bled so copiously that he had to be closed up right away. The obstruction remained and there was no way to get at it.

Two weeks after the failed attempt at bowel surgery, the teams met and agreed to tell Miss Strawson that their medical judgment was that Billy was not going to make it. Another care committee meeting was held. Once again, all medical personnel spoke with one voice. But this time, it was to tell Miss Strawson that there was no hope of recovery.⁷

Two days after the meeting, all life-support mechanisms other than the ventilator were withdrawn. Thirty-six hours after that, in the first week of his sixth month in the hospital, Billy died.

Perhaps the kind of decision-making that led to the continuation of Billy's treatment is mandated by the principle of "erring on the side of life". But while erring on the side of life (by continuing treatment for too long) may be better than erring on the side of death (by discontinuing treatment too soon), it is better still not to err at all.

Then again, maybe we ought not take the principle of erring on the side of life in a perfectly literal sense. What the principle may mean is that it is always right to pursue virtually every chance of life, that a choice on the side of life is never actually an error at all. Now there is certainly nothing wrong in a person's using this 'on the side of life' principle to make decisions for him or herself. But is it obviously acceptable to use it to make decisions for someone else, such as a suffering child? Is it fair to proceed on the assumption that it is never an error to continue to treat a PICU patient so long as there is any possibility at all of benefit?

I do not mean for those questions to be rhetorical. I honestly do not know how to answer them. But it does seem to me that at least sometimes the subject of discontinuation is not broached because of a belief that it would be a betrayal of proper concern for a child. What I hope the case of Billy makes clear is that a timely and open discussion of the subject may be just what proper concern demands.

Endnotes

- 1 Five years ago, I spent several months in a pediatric intensive care unit in the USA doing observational research (a project that was approved by the hospital's internal review board). I was graciously allowed to follow physicians on daily rounds and to attend meetings between various medical personnel. I also observed the conduct of the parents of some of the patients when physicians were not present, but only after I had explained to the parents that I was a philosophy professor (not a medical doctor) doing research on medical ethics. The case described here is one I observed during that time. I have changed

names and other inessential detail to protect the confidentiality of the people involved. The points I make here are also informed by my experience of serving on medical ethics committees in three different US hospitals over the course of the last 10 years. I readily acknowledge, however, that my experience may not be entirely typical, and that I do not have the data to make claims about pediatric critical care in general as it is currently delivered in hospitals throughout North America and Europe. I welcome responses from physicians, nurses, and parents who have spent time in pediatric intensive care units; I am particularly eager to hear about the extent to which the case I describe here is similar or dissimilar to others' experiences.

- 2 For discussion of the use of narrative in the treatment of very sick children, see Carter, M. A., & Robinson, S. S. (2001). A narrative approach to the clinical reasoning process in pediatric intensive care: The story of Matthew. *Journal of Medical Humanities*, 22, 173–194.
- 3 A clear statement of the role children and parents should play in pediatric decision-making, along with a good bibliography, can be found in Committee on Bioethics (1995). Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*, 95, 314–317. See also Kunin, H. (1997). Ethical issues in pediatric life-threatening illness: Dilemmas of consent, assent, and communication. *Ethics and Behavior*, 7, 43–57. For discussion of methods of discussing death with very sick children, see Hurwitz, C. A., Duncan, J., & Wolfe, J. (2004). Caring for the child with cancer at the close of life. *Journal of the American Medical Association*, 292, 2141–2149.
- 4 For discussion of methods of resolving disagreements between different caregivers of a single patient, see Randolph, A. G., Zollo, M. B., Egger, M. J., Guyatt, G. H., Nelson, R. N., & Stidham, G. L. (1999). Variability in physician opinion on limiting pediatric life support. *Pediatrics*, 103, 46; Mitchell, C., & Truog, R. D. (2000). From the files of pediatric ethics committee. *The Journal of Clinical Ethics*, 11, 112–120; Studdert, D. M., Burns, J. P., Mello, M. M., Puopolo, A. L., Truog, R. D., & Brennan, T. A. (2003). Nature of conflict in the care of pediatric intensive care patients with prolonged stay. *Pediatrics*, 113, 555–558.
- 5 For discussion of the role of nurses in PICU decision-making, see Garros, D., Rosychuck, R. J., & Cox, P. N. (2003). Circumstances surrounding end of life in a pediatric intensive care unit. *Pediatrics*, 112, 371–370.
- 6 For discussion of the ethical importance of transparency in the doctor–patient relationship, Brody, H. (1989). Transparency: Informed consent in primary care. *Hastings Center Report*, 19, 5–9.
- 7 For discussion of end-of-life decision in pediatric settings, see Sahler, O. J. Z., Frager, G., Levetown, M., Coh, F. G., & Lipson, M. A. (2000). Medical education about end-of-life care in the pediatric setting: Principles, challenges, and opportunities. *Pediatrics*, 105, 575–584; Garros, D., Rosychuck, R. J., & Cox, P. N. (2003). Circumstances surrounding end of life in a pediatric intensive care unit. *Pediatrics*, 112, 371–370.

Biographical Note

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