Watching Brian die: the rhetoric and reality of informed consent

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ABSTRACT Two years ago, my brother-in-law was injured in a catastrophic industrial accident, which left him with second and third degree burns over 95 percent of his body. Writing both as a family member and as a sociologist, I analyse how his doctors increased their decision-making authority at the expense of informed consent, explore why they did so, and discuss the consequences for families when informed consent is not obtained. I also discuss the difficulties of achieving informed consent when family members have conflicting views on treatment. The conclusions use this story to reflect on the problems of implementing informed consent in clinical practice and on what these problems tell us about US doctors’ continuing power and clinical autonomy.

KEYWORDS bioethics; burns; informed consent; physicians

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Two years ago, my brother-in-law, Brian, was injured in a catastrophic industrial accident, which left him with second and third degree burns over 95 percent of his body and with strong indications that he had suffered a severe inhalation injury.

Brian’s accident occurred literally in sight of a major hospital with a regional burns unit, and he was brought to the hospital within minutes. Following the accident, Brian remained in a strange limbo between life and death – unconscious although not comatose, and kept alive by aggressive medical treatment and an ever-increasing assortment of drugs and machines. Burned everywhere except his genitals and the soles of his feet, bandaged from head to toe with only his face showing, and swollen grotesquely, Brian’s appearance was literally nightmarish; no one who saw him slept well afterwards. Each day brought minor crises, and each week brought a major crisis that made death seem imminent – as indeed it was, for Brian died three and a half weeks after the accident.

During the days following the accident, various members of my family
increasingly began to wonder whether the doctors were making treatment decisions that should have belonged to Brian’s wife, Lisa; withholding information she needed to make treatment decisions; or taking actions that could result only in a certain death or an unbearable life. Probably no one could fully avoid this last thought, given the sight we saw each day as we entered the burns unit: a woman, burned six months earlier and far less severely than Brian, staring at a television on the ceiling while wrapped in bandages from head to toe, with her arms and legs splinted, immobilized, and stretched out as if she were crucified on her bed. This was the fate awaiting Brian should he survive.

These issues weighed heavily on my mind. My husband and I had first received word of Brian’s injuries by telephone soon after the accident, and had flown a thousand miles to join the family later that night. As a medical sociologist, I knew something of the devastation wrought by severe burns and thus had assumed both that Brian would die and that death would be a mercy (see Kliever, 1989). I also, however, knew that medical culture trains doctors to value technological interventions and to view death as failure (Katz, 1984; Guillemin and Holmstrum, 1986; Klass, 1987; Weir, 1989), and as a result feared that Brian’s doctors might adopt a recklessly aggressive course of treatment.

On the other hand, I also knew that, before beginning treatment, doctors must obtain informed consent from the patient or, if the patient is not competent, from the patient’s closest relative (in this case, Lisa). Yet I knew that doctors typically believe that they alone should make clinical decisions, and that they therefore establish typically hierarchical rather than egalitarian relationships with patients and their families (e.g. Mishler, 1981; Guillemin and Holmstrum, 1986; Anspach, 1993). This ideology is so firmly held that the rise of living wills, hospital bioethics review committees, and professional ethics committees designed to change it appears to have had little impact on medical decision-making (Guillemin and Holmstrum, 1986; Annas, 1991; Anspach, 1993; SUPPORT Principal Investigators, 1995; Bosk and Frader, 1998).

Previous studies have documented several ways doctors, whether intentionally or not, can increase their decision-making authority and reduce that of patients and families (Katz, 1984; West, 1984; Mannon, 1985; Fisher, 1986; Guillemin and Holmstrum, 1986; Waitzkin, 1991; Zussman, 1992; Anspach, 1993). First, doctors may make decisions without asking the patient’s or family’s opinion, on the assumption that they would agree with the doctors. Second, doctors can respect a patient’s or family’s wishes, but only after first shaping those wishes through selectively providing information about the situation. In addition, doctors can cut off discussions and questions that they consider irrelevant or uncomfortable, give general rather than specific answers to questions, give information only when directly asked, or use euphemisms that confuse lay persons. Finally, in the rare cases in which patients or families actively challenge medical decisions, doctors can ignore
them, arguing that lay persons who disagree with doctors must be too psychologically disturbed to decide rationally, that lay persons are unqualified to make what the doctors view as essentially technical decisions, or that families that take responsibility for life and death decisions experience additional guilt and grief in the long run. As a result, only the most determined, assertive, and resourceful lay persons can challenge doctors’ decisions successfully (Zussman, 1992). This knowledge led me to fear from the start that the doctors would not give Lisa the information and authority that she needed to act as Brian’s surrogate decision-maker – a fear that would soon prove warranted.

Since Brian’s death, I have had the chance to reflect more on our experiences, and have come to see them as an example both of the difficulties of implementing informed consent in the complex, murky terrain of clinical practice and of the consequences for families when informed consent is not obtained. This article is my attempt to make something useful from this tragedy. Writing, then, both as a family member and as a sociologist, I first describe how the doctors, whether intentionally or not, arrogated decision-making authority, and compare the actions of Brian’s doctors to those observed in other studies of intensive care units. I then describe the impact of this on the family, explore why the doctors arrogated decision-making, and discuss what this suggests about the continuing power and clinical autonomy of US doctors.

As a case study, some of the limitations of this article are obvious. In addition, although I spoke extensively about these issues at the time and afterwards with Lisa and her family, I spoke only minimally with Brian’s brother and parents. Similarly, all adult members of Lisa’s immediate family read and commented on this article in draft, but none of Brian’s relatives did so. As I will describe, tensions developed between the two families during the days following the accident, and I feared that talking with Brian’s family about the issues might worsen these already strained relationships. I did, though, speak briefly with Brian’s brother. An evangelical Christian who, like us, lived in another state, he had spent most of the first week after the accident at the hospital in prayer, and had then returned home. He claimed that he had not discussed Brian’s treatment with either his parents or the doctors.2

I had hoped to interview the doctors, but did not want to do so until after I received a copy of Brian’s medical records, for fear that an interview might either irritate the doctors or raise fears of a lawsuit, and that subsequently they might make it difficult for us to get the records. Unfortunately, although not surprisingly, Lisa (the only person who legally could request the records) could not bear to go to the hospital for some months after the accident. By the time I received the records, enough time had elapsed that I concluded that contacting the doctors would not be useful, especially since I would have had to do so by telephone. Thus I can only tell this story from my perspective and, to a lesser extent, that of Lisa and her family.
Throughout his hospital stay, decisions about Brian’s care were complicated by two facts: that he never regained consciousness after leaving the emergency room and that Brian’s father, Jack, and his wife, Lisa, held somewhat different views regarding treatment and decision-making. These facts would make it harder for the burns unit doctors to involve the family in decision-making and easier for the doctors, whether intentionally or not, to arrogate decision-making authority for themselves.

Because Brian remained unconscious, no one could truly know what he would have wanted for himself. He left neither a living will nor a medical power of attorney. He had, however, told Lisa previously that he would not want to live if his quality of life was ever compromised substantially. This seemed a likely outcome of his injuries, especially since he worked with his hands as a skilled technician and found many of his greatest pleasures in physical activities.

When first brought to the emergency room, Brian was briefly conscious. At that point, the attending doctor from the burns unit, Dr Thompson, told him that he was severely burned, that his chances of survival were very small, and that any treatment would be ‘long, arduous, and painful.’ Dr Thompson then asked Brian if he wanted to live, and Brian replied affirmatively (although it seems highly unlikely that Brian – in shock, in pain, and with little understanding of his situation – had either the information or the capacity to make an informed decision at this point).

In an emergency of this sort, of course, any additional time spent trying to inform Brian would have reduced his chances of survival. In these circumstances, legal precedent, medical protocols, and insurance regulations authorize doctors to begin treatment if they consider it warranted, postponing any decisions about the appropriateness of continuing treatment until either the patient’s prospects become clearer, the patient regains decision-making capacity, or a spouse or other legally accepted surrogate decision-maker arrives on the scene. According to Robert F. Weir, recent legal cases suggest an emerging consensus that:

[such a] surrogate has the legal authority to refuse all forms of life-sustaining treatment on the behalf of the patient . . . as long as the surrogate’s decision reflects the patient’s own views on life-sustaining treatment or is based on a determination of the patient’s best interests. (1989: 147)

The right to refuse treatment is legally clearest in cases like Brian’s, in which treatment is highly invasive and prognosis is poor. (Weir, 1989: 150)

Lisa reached the hospital not long after the accident. The doctors briefly informed her of the situation, but did not indicate that she needed to make any decisions about Brian’s treatment. At this point, then, the doctors apparently assumed that Lisa would agree with their decisions (see Mannon, 1985; Guillemin and Holmstrum, 1986; Zussman, 1992; Anspach, 1993).

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My husband and I arrived at the hospital early the next morning, where the other relatives already had gathered. I was startled to find Brian still alive – I had not thought such injuries were survivable – and worried that the doctors might have embarked on a course of futile and perhaps even cruel treatment. Both Brian’s relatives and mine – all of whom were closer to Brian than I because they lived much nearer to him – seemed stunned and traumatized, neither supporting nor questioning the doctors’ actions. This led me to wonder from the start what I could or should say to them, especially to Lisa.

In the meantime, I dealt with my fears primarily intellectually rather than emotionally by focusing on obtaining information. I began by speaking privately that first day with the senior resident. Choosing my words carefully, so as not to become labeled a trouble-maker, I asked who held legal decision-making authority. He answered that Lisa held sole authority as long as Brian remained unconscious, and mentioned that she might consider issuing a ‘do not resuscitate’ (DNR) order. He explained, however, that doing so was of little importance, because something else almost certainly would kill Brian before cardiac failure and because resuscitation almost certainly would not succeed. That same day he privately told Lisa that she had legal decision-making authority and that she could issue a DNR order, although he did not offer any details.

I then asked the doctor if there were any circumstances in which they would ask Lisa’s permission before beginning various treatments – mentioning as examples the decision to use kidney dialysis, to give antibiotics, or to use a ventilator. His answer was that there were none. He mentioned without explanation that in some parts of the country, doctors routinely offer only palliative care to any patient who suffers more than a 70 percent burn – much smaller than Brian’s injuries – but stated that he regarded withholding any treatment as unethical, for ‘we have no right to play God.’

Like the argument that medical intervention is purely a technical matter, the argument that intervention is a straightforward moral imperative makes it impossible for lay persons to challenge doctors’ treatment decisions. This argument serves doctors well only if they favor continuing aggressive treatment while families favor discontinuing it. In most cases, however, both doctors and families favor aggressive treatment. Moreover, when disagreements arise, most often it is doctors who favor discontinuing and families who favor continuing treatment (Mannon, 1985; Guillemin and Holmstrum, 1986; Zussman, 1992; Anspach, 1993). This may explain why previous studies of ICUs have not observed doctors making this argument.

My conversation with the senior resident reinforced my fears regarding both the doctors’ commitment to aggressive treatment and their unwillingness to involve Lisa in decision-making. Subsequent discussions similarly indicated that the doctors regarded Brian’s one-word assent to treatment – given when he was less than fully informed and had substantially diminished decision-making capacity – as sufficient authorization not only to begin but
also to continue aggressive treatment. For example, a week after the accident, Dr Thompson met with the family following rounds to discuss the case. (We had returned home the day before, after concluding that we could not predict when the doctors would meet with us or when the situation might change.) This meeting marked the first time that family members publicly—if tentatively—questioned what survival might mean for Brian. In response to their questions, Dr Thompson stated that he ‘was not ready to discuss these issues now,’ and that, based on his interchange with Brian, he would proceed with aggressive treatment unless Brian woke up and instructed him otherwise. When Lisa mentioned her previous conversation with Brian regarding whether he would want to survive if severely disabled, Dr Thompson told the family—in a manner that both Lisa and her parents described as dismissive—that he routinely ignored ‘kitchen table discussions’ patients might have had while still healthy about withholding life-supports. It seems, then, that although the doctors formally recognized both Brian’s and Lisa’s legal rights to informed consent, they defined those rights very narrowly, providing themselves with an additional means (not previously noted by scholarly observers) for maintaining decision-making authority.

Lisa herself would soon come to the same conclusion. When I tape-recorded her recollections six months after the accident, and asked what she thought the doctors defined as her role in decision-making, she replied:

To say ‘okay’ to whatever they wanted. I think the only reason they ever asked me for consent was because they were required to in certain situations. In the beginning I’m sure they defined my role as ‘stand back and let us do our job.’ There was no consultation at all with me for the first 24 hours or so after the accident. And then later when I would try to get more info, their reactions ranged from ‘this does not compute’—as if they had never heard questions like these before—to almost animosity.

The difficulties Lisa faced in getting information about Brian’s prospects left her highly ambivalent about the care he was receiving. She never concluded that it would be best if Brian died or if treatment were halted. Yet questions about Brian’s quality of life should he survive continued to haunt her. As she put it: ‘The one thing I stressed from the beginning to Thompson is “I don’t want [Brian] to survive as just a technological miracle. I’m really clear about that”.’ As the days passed, however, first Brian’s lungs, then his stomach, and then his kidneys failed, while pneumonia and, increasingly, other bacterial, viral, and fungal infections assaulted his body. Each of these events led Lisa to raise at least tentative questions with the doctors about whether Brian’s continued survival was in his best interests and whether certain treatments, especially kidney dialysis, made sense. The responses she received, however, like those given to the families observed in other ICUs by Guillemin and Holmstrum (1986), Zussman (1992), and Anspach (1993), were both too vague and too narrow to answer her questions. As she explained:

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What was frustrating for me was... grappling with the issue of whether we are just prolonging his pain or are we really treating him toward recovery? In asking some of the things that I needed to know to understand about the future, that's where it got really frustrating. I kept getting the response 'well, he'll keep his hands and his feet,' and had trouble getting them to move beyond that. Or they would say 'we can arrange for you to talk to Ray' [a survivor of a severe burn who now worked for the hospital], who was a success story. But nobody wanted to point to the room next door to Bob, where that woman had been lying for six months... . There was this black hole whenever you wanted to know 'well, what if it isn't a success story?'

In the first few days after the accident, Lisa also raised similar questions with me, giving me the chance to share with her some of the information I had been gathering. In addition to talking with the senior resident, I also had talked on one occasion to Brian’s nurse, had several long telephone conversations with friends who were doctors, and had gone to the hospital library and later to a local medical school library to read about severe burns. The pictures I saw and descriptions I read in this library research left me, for the first time since the accident, sobbing near-hysterically, and more horrified than before at Brian's treatment, which increasingly seemed like mere experimentation.

When I told Lisa of my research, and asked her whether she wanted to know what I had learned, she unequivocally said yes. I then told her that burns of this sort would likely lead to life-long pain and risk of death from infection. I also told her that, according to Brian’s nurse, the pain would impair Brian's ability to concentrate to such an extent that he would be unable to read or attend college (a prospect that had offered the one potentially positive outcome of the accident) for some time. I did not explicitly state my views on Brian’s treatment, both because I lacked the courage and because I wanted Lisa to form her own opinion, but I am sure that something of my own views came through.

I was not the only family member who questioned whether aggressive treatment made sense. Those of us who did so, however, discussed our views only guardedly and only with those we suspected would agree. Similarly, those who favored aggressive treatment tended to keep their views to themselves. The one exception was Brian’s father, Jack, who quickly emerged as a vocal supporter of aggressive treatment, stating that he wanted everything possible done to keep Brian alive, regardless of Brian’s eventual quality of life. Indeed, Jack’s commitment to aggressive treatment extended to possibilities that the doctors had ruled out explicitly, such as a lung transplant. That philosophy also led Jack to tell Lisa that he would have trouble forgiving her should she withhold any treatments and to tell her father that withholding treatment would be the same as killing Brian. Brian's mother, on the other hand, never discussed her views with any member of Lisa’s family. Her silence ‘spoke’ eloquently about the difficulties we were all facing in trying to sort out and communicate our views.
In an ideal scenario, either the doctors or other members of the ‘care team’ – nurses, pastoral counselors, social workers, psychologists – would have facilitated discussion of the issues, helping individuals to explore their feelings and options, seek needed information, and reach consensus or at least tolerance for divergent viewpoints. This was never attempted, despite Lisa’s request for such a discussion.

Instead, the doctors seemed to avoid these issues while the social workers, psychologists, and pastoral counselors seemed to view their job as ‘cooling out’ the family. For example, when Lisa’s mother and father (a minister who had served for five years on a hospital medical ethics committee) asked one of the pastoral counselors to facilitate a family discussion about possibly terminating care, the counselor dismissed the request with the statement that: ‘Well, I’d trust any family member of mine to Dr Thompson’. A similar meeting with a social worker also yielded no results. Even worse, both the pastoral counselor and one of the social workers implied in conversations with Lisa that she was only questioning the doctors’ decisions because she did not want to be burdened with a sick husband. (Similarly, Stinson and Stinson, 1979; Guillemin and Holmstrum, 1986; Anspach, 1993; found that parents who opposed aggressive treatment for premature infants were labeled by staff as either psychologically disturbed or as not really wanting a baby.)

These responses particularly infuriated Lisa’s father. His concerns led him to request information about the hospital’s ethics committee. The glossy brochure he received from one of the chaplains mentioned that the committee had established ethical guidelines for medical care. Despite two attempts by Lisa’s father and one by her brother (a local lawyer), neither was able to obtain the guidelines. After returning home, I tried to obtain more information about how ethics committees work, and whether the ethics committee at this hospital could or should play a role. My conversations with a friend who works in health law and a bioethicist familiar with this particular hospital led me to conclude that ethics committees typically are structured to assist doctors in dealing with patients and their families rather than to help patients and families. (See for similar conclusions Paris et al., 1993; Bosk and Frader, 1998) I debated calling the ethics committee myself, but concluded that it would be unlikely to make much of a difference and that it was improper for me to do so without Lisa’s permission – which I was loath to seek for fear I would seem to be pushing my views on her. With much trepidation, I did ask the bioethicist with whom I had talked earlier to look into the situation, but did not speak with her subsequently. As far as I know, the committee played no role in Brian’s case; none was noted in his medical records.

Similarly, no one from the hospital helped the family to accept Lisa’s decision-making authority. I do not know if the doctors ever told Brian’s parents that Lisa had sole decision-making authority, but I do know they did not tell any member of Lisa’s family other than me. Nor, according to
Brian’s brother, did they tell him. Moreover, they continued to involve Jack in all discussions about Brian’s treatment, making it difficult for Lisa to raise her concerns privately with the doctors despite her request that they set aside time to speak with her alone:

And then I had to constantly battle the burn unit staff – especially the doctors – because they wanted everything to be a family thing. I talked to the social worker, chaplain, doctors, and tried to get someone to hear that I understand it is best if there is family participation, but what we have here is a conflict between my views and Brian’s parents’ views, and I need some help. Because in this situation it’s not necessarily beneficial to have these joint conferences with the whole family. And I couldn’t get them to listen.

In addition, Dr Thompson often talked to Jack early in the morning before Lisa arrived at the hospital, relying on Jack to relay information to Lisa. In one instance Dr Thompson decided to hold the weekly family meeting earlier than had been agreed on and before Lisa had arrived, on the grounds that he could always ‘fill her in’ later (although he did not in fact do so). Finally, according to Lisa and her parents, when meeting with the family, he and the other doctors often seemed both verbally and non-verbally to address their comments to Jack rather than to Lisa. These actions led Lisa to believe that Dr Thompson and the other doctors were avoiding her and instead communicating to the family through Jack. Since Jack had no legal decision-making authority, undercutting Lisa’s authority reinforced the doctors’.

Other factors also reinforced the doctors’ authority at the expense of Lisa’s. Most critically, and as researchers have documented in other ICUs (Mannon, 1985; Guillemin and Holmstrum, 1986; Zussman, 1992; Anspach, 1993), the doctors never gave the family enough information to develop an informed understanding of Brian’s prospects or to reach an informed decision about his treatment. After the first day, when we were told that he had only a 1 percent chance of surviving, the doctors offered almost no information about Brian’s long-term prospects. They did not change this 1 percent estimate until Brian’s final hours, and never gave us any meaningful information about what his life would be like if he did survive. We were told, for example, that Brian was not currently in any pain, but never told that individuals who survive severe burns always experience significant disability and long-term, debilitating pain, making suicide all too common. Similarly, when asked what Brian’s life would be like in the long run, the doctors either gave vague answers (‘he won’t have fine motor skills in his hands’) or explicitly told us not to worry about these issues until we knew whether he would survive that long. The latter answer, of course, begged the question as to how we could know if it was worth helping Brian to survive without knowing what his life would be like if he did. For this reason, I encouraged Lisa to develop a specific list of questions for the doctors that could not be dismissed with vague answers, such as how long it would be
before Brian could hold and read a book, type at a keyboard, or pick up his
two young daughters. Lisa did not act on this suggestion because of her
increasing sense that, with each question she asked, the doctors became
more dismissive and, occasionally, hostile, and that she was therefore help-
less to affect Brian’s care. Moreover, the apparent differences between her
perception of the situation and the doctors’ perception, and her increasing
marginalization in Brian’s care, led her to wonder whether she was losing
her ability to judge the situation rationally.

The doctors’ withholding and selective offering of information seemed to
reflect a desire to convince the family to accept their decision to treat
aggressively. Thus when Brian’s mother asked in a family conference if
Brian would retain his ears, the doctor replied that it would not matter,
given recent advances in plastic surgery. Similarly, according to several
family members, Dr Thompson told them that ‘so long as Brian’s lungs
begin working, we can fix everything else’ – a statement that was patently
untrue, as the greatest danger to burn patients comes from infections. When
Brian, who had been hooked to a ventilator from the start, began taking an
occasional breath, the doctors claimed that he was now ‘breathing on his
own’. When asked, however, the nurses (who always proved far more forth-
coming than the doctors and were much more helpful to Lisa than any other
hospital staff) showed us on the monitor how his breaths were both too
shallow and too infrequent to sustain life. By the same token, with each
physical crisis that Brian survived, thanks to the doctors’ intensive inter-
ventions, the doctors emphasized how he was a strong man with a ‘strong
will to live’. One could have argued with equal logic that Brian was fighting
to die, but the doctors would not let him do so.

In the end, Brian’s condition began deteriorating so rapidly and com-
pletely that the doctors had no further treatments to try. A few days earlier,
a new resident had joined the staff. Alone among his colleagues, this doctor
seemed to take Lisa’s concerns seriously. A long conversation with him
during Brian’s final days greatly helped Lisa, both by allowing her to
express her feelings and by giving her a much greater understanding of how
the doctors made their decisions about treatment. When this resident rec-
ommended that Lisa give permission to withdraw the drug that kept
Brian’s heart beating, Lisa accepted his recommendation, and Brian died
that night.

The impact of arrogating decision-making authority

The doctors’ inability or unwillingness to share decision-making authority
with the family had both positive and negative effects. On the positive side,
by removing decision-making from the family, the doctors left Jack with the
belief that he had done everything in his power to fight for his son’s life, and
enabled Lisa to avoid responsibility for making some heart-wrenching
decisions. As she later observed:
I can see positive consequences in the way it ended... The positive about all this was that after the fact for whatever reason I’m glad that every possible avenue was tried. Because there’s enough questions you ask yourself and enough guilt you lay on yourself that for me I think it’s good to know that every possible thing was done. So I don’t have the guilt of maybe I terminated things too early.

The doctors’ actions also allowed Lisa to avoid confronting Jack directly and risking permanent damage to their relationship. This was especially important to Lisa, as she recognized from the start that her girls might lose their father and would need a relationship with their grandfather. It is also possible (although unverifiable) that keeping Brian alive for so long benefited the family by giving some individuals time to come to terms with his eventual death.

On the other hand, the doctors’ lack of commitment to shared decision-making had several harmful effects. The doctors’ consistently optimistic interpretation of Brian’s condition and unwillingness to answer hard questions about his prognosis left some family members woefully unprepared for his eventual decline and death. Conversely, those family members who believed Brian had virtually no chance to survive, and dreaded even more what his life might be like if he did, experienced three and a half weeks of anguish, during which they could only regard Brian’s treatment as a medical experiment rather than meaningful clinical care. In addition, the doctors’ actions added to Lisa’s trauma, by leading her to question her sanity and judgment.

Not surprisingly, this experience left some family members cynical about and even fearful of medical care, by suggesting that doctors might be more interested in their own careers or egos than in their patients’ welfare. Fortunately, several of us had turned to friends who were doctors for advice during this experience. Almost unanimously, these friends were appalled by the situation, which helped us to avoid generalizing from Brian’s doctors to all doctors. Nevertheless, some family members (including my husband) subsequently wrote living wills to protect themselves from overly authoritarian doctors. (I had had a living will for some time.) Others have not done so in part because they no longer believe such documents offer much protection. As Lisa said to me six months after Brian’s death:

I remember when [your husband] sent his living will to Mom and Dad and I read it and I applied Brian’s experience to that, I realized that that piece of paper isn’t worth hardly anything. If a doctor thinks it doesn’t apply to your situation or defines some of the key terms in ways differently from you, you’re powerless to do anything about it.

To the extent that the doctors’ unwillingness to share decision-making authority prolonged aggressive treatment, that refusal also had the effect of threatening the family’s financial resources, and thereby adding to the emotional stress of the situation. Fortunately, Brian’s medical bills were covered by workers’ compensation, but each additional day away from
work put Lisa’s job further in jeopardy. Lisa was fortunate that she was paid; others might not have been. In addition, Brian only had accidental death insurance, rather than regular life insurance, to protect his wife and their daughters should anything happen to him. That policy only paid if he died within thirty days after an accident. If extraordinary medical measures had continued to keep Brian hanging on to life for even a few days longer, the policy would have been worthless. No one, of course, would have regretted the loss of the insurance money if Brian had a reasonable chance of surviving. If, however, he had no real chance of doing so, then the loss of insurance money would have been a cruel additional blow.

Equally important, each day in limbo further strained the family’s emotional resources. During the three and a half weeks in intensive care, Brian’s two young daughters lost not only all meaningful contact with their father, but also much of their usual contact with their mother, who spent many hours at the hospital. Normal daily routines, too, fell by the wayside. Thus, the time in intensive care added a month of chaos, especially for the girls, to what would have been a devastating loss in any circumstances. In addition, that month of chaos was punctuated by medical crises that sapped the family’s emotional resources by forcing us repeatedly to confront Brian’s imminent death.

Finally, a palpable division developed between some members of Brian’s and Lisa’s families. Given the different philosophies and subject positions that these individuals had brought to the situation, this division may have been inevitable. Nevertheless, it is possible that had the hospital staff encouraged and mediated open discussions among family members, some middle ground might have been found, and individuals might have been able to express their views in ways that did not threaten their relationships with each other.

Discussion

The central question that emerges from this story is why were Brian’s doctors so unwilling to share decision-making authority? The simplest answer is because they were ICU doctors. Previous studies consistently have found that ICU doctors define informed consent in ways that give them tremendous leeway to assert their own decisions (Mannon, 1985; Guillemin and Holmstrom, 1986; Zussman, 1992; Anspach, 1993). Those studies find that except in the most hopeless of cases, ICU doctors almost invariably begin aggressive treatment without consulting the patient or the family. As the clinical situation becomes clearer, doctors either define the situation in ways that secure the family’s support for their decisions or find grounds for ignoring the family’s decisions. Brian’s story adds to our knowledge of how ICU doctors arrogate decision-making authority, while confirming what others have observed about medical decision-making.

In Brian’s case, the doctors’ unwillingness to share decision-making
authority also may have reflected their commitment to aggressive treatment and consequent concern that Lisa might press to limit treatment. For this reason, we need to look further into the philosophical, legal, professional, and psychological reasons why these doctors appeared to support aggressive treatment.

A basic premise of medical culture is that aggressive, invasive, treatment is more valued than other treatments (Katz, 1984; Guillemin and Holmstrum, 1986; Klass, 1987; Weir, 1989). This is especially true among surgeons. It is thus not surprising that Brian’s doctors – who, unlike the ICU doctors studied by other sociologists, were all surgeons – seemed philosophically committed to aggressive treatment, even in a case that seemed almost certainly hopeless.

Legal factors also may have encouraged Brian’s doctors to favor aggressive treatment, and thus to resist involving in decision-making anyone who might want to limit treatment. Recent court decisions unanimously suggest that doctors who withhold or withdraw treatment will not be found legally liable when patients die, so long as those deaths are caused by an underlying medical condition and the doctors believe they are acting in the patient’s best interests (Weir, 1989: 152). However, the high malpractice premiums that US doctors pay yearly, combined with recurrent stories about doctors who have been sued, have created an atmosphere in which doctors’ fear of lawsuits sometimes may affect their clinical decisions. Such fears naturally would have been amplified for Brian’s doctors by Jack’s stated opposition to limiting treatment and by Lisa’s ambivalence about doing so.

In addition, professional factors – specifically, the research mandate of regional burns units – may have encouraged Brian’s doctors to support aggressive treatment and therefore to resist sharing decision-making. Sociologists have concluded that the unusual commitment of doctors on neonatal ICUs to aggressive care reflects the strong research mandate of these units, which emphasizes studying how to keep alive ever-younger babies (Guillemin and Holmstrum, 1986; Anspach, 1993). I would hypothesize that the main mandate of burns unit doctors is to learn how to keep alive those with ever-more-extensive burns, in the hopes that such knowledge will help other patients in future. By this measure, keeping Brian alive for three and a half weeks was a success – even though he died. Research interest in Brian’s case would have been further heightened by the highly unusual source of his burns – no similar burns cases appear in the medical literature except for one very famous case in which all victims died immediately – as scholars have observed often that medical culture teaches doctors to place the most value on treating and researching rare illnesses and conditions (e.g. Ludmerer, 1985; Mizrahi, 1986; Klass, 1987; Scully, 1994).

Finally, it is possible that the doctors’ commitment to aggressive treatment and apparent unwillingness to share decision-making reflected their unusually high sense of identification with Brian. As mentioned earlier,
most burns patients are working or lower class. Although neither Brian nor Lisa had finished college, the other members of the family – all of whom were at the hospital within hours of the accident – had. Since Brian was unconscious and Lisa less outspoken than other family members, the impression the doctors were left with may have been that of a family much more like their own than was typical. In addition, the majority of burns in adults are obviously caused by the burned individual, and linked to smoking, alcohol or drug use, or psychiatric disturbances (including suicide attempts) (MacArthur and Moore, 1975; Brodzka et al. 1985; Mannon, 1985). Studies repeatedly have found that doctors have limited sympathy for patients of this sort (e.g. Klein et al., 1982; Mizrahi, 1986; Smith and Zimmy, 1988). In contrast, Brian’s injuries resulted from a ‘normal accident’ (Perrow, 1984), caused more by a complex technological system than by any single individual’s actions. These factors, coupled with the fact that Brian was a big, healthy man with young children, may have increased the doctors’ commitment to doing everything they could to improve his chance of surviving.

The second major question to emerge from this story is why, given the doctors’ apparent unwillingness to involve Lisa in clinical decision-making, they seemed more willing to involve Jack? Again, part of the answer to this latter question can be found in previous studies. Other scholars have found that doctors are most likely to involve patients and families in decision-making when those individuals are college-educated professionals (Mannon, 1985; Street, 1991; Zussman, 1992; Anspach, 1993). Although Lisa is intelligent and well read, she had not graduated college and did not hold a fully professional position. In contrast, Jack is a confident and wealthy businessman. In addition, previous research suggests that male doctors feel most comfortable speaking with male patients and relatives (West, 1984; Fisher, 1986; Waitzkin, 1991). This would also partially explain the different reactions to Jack and to Lisa, as all Brian’s doctors were male.

Similarly, previous studies suggest that doctors are most likely to share decision-making authority with patients and families who aggressively seek information and involvement (Mannon, 1985; Street, 1991; Zussman, 1992; Anspach 1993). Whereas Jack is comfortable stating his position assertively and aggressively seeking his goals, Lisa tends to make statements and decisions deliberately and quietly. It is possible that, if Lisa had more forcefully asserted her wishes about Brian’s treatment or about her role in that treatment, the doctors would have involved Lisa further in decision-making – but it is equally possible that they would simply have become more hostile.

The differences between the doctors’ communications with Jack and Lisa also may have reflected their stated commitment to a ‘family model of care.’ Ironically, rather than helping the family, this model gave the doctors an ideological justification for treating family members as interchangeable units, creating problems for Lisa not discussed in previous studies. Thus if
they told Jack something, they appeared to feel no obligation to inform Lisa, despite their stated belief that she held sole decision-making authority. This occurred more and more often over time, for, as Lisa’s differences with Jack grew, she began coming to the hospital only at night to avoid him. As a result, the doctors were far more likely to encounter Jack than Lisa.

Finally, I would argue that although the doctors spent more time talking with Jack, they in fact did not offer him any greater involvement in decision-making: Jack received no more information than Lisa, and no additional opportunities to challenge the doctors’ decisions. Overheard conversations between Jack and the doctors consisted mostly of vague statements from the doctors about Brian’s condition and ‘will to live’ and laudatory comments from Jack about the terrific job the doctors were doing. The doctors had no reason to avoid such conversations, which bolstered their authority and sense of moral goodness while in no way challenging their authority. Indeed, Mannon (1985) notes that doctors define showing gratitude as an essential part of family members’ role on a burns unit. In contrast, although Lisa never openly challenged the doctors, neither did she show gratitude to them. Thus speaking with Lisa was never a fully comfortable experience for the doctors.

Conclusions

Previous studies have documented the different ways doctors, whether intentionally or not, can increase their decision-making authority (Katz, 1984; West, 1984; Mannon, 1985; Fisher, 1986; Guillemin and Holmstrum, 1986; Waitzkin, 1991; Zussman, 1992; Anspach, 1993). As was true in those studies, Brian’s doctors made decisions without asking Lisa’s opinion, ignored her wishes when they disagreed with her opinions, or respected her wishes only after first shaping them through selectively providing information. They limited the information available to her by cutting off discussions and questions which they considered irrelevant or uncomfortable, giving general rather than specific answers to questions, giving information only when directly asked (if then), or using euphemisms (such as ‘breathing on his own’) that made it difficult for Lisa to understand Brian’s situation. At the same time, and also as documented in other studies, doctors defused challenges by defining their actions as purely technical matters that lay persons could not comprehend, while hospital staff defused challenges to doctors’ authority by implying that lay persons who disagreed with doctors must be psychologically disturbed.

Brian’s doctors also increased their decision-making authority in ways not observed in previous studies of ICUs. First, by defining Brian’s one-word assent to treatment in the emergency room as ‘informed consent,’ and by defining prior ‘kitchen table discussions’ as irrelevant to understanding Brian’s wishes, they could define themselves as the persons best able to speak for Brian’s wishes. Second, by defining medical intervention as a
moral imperative, they could define any discussions about withholding or withdrawing care as immoral. Third, by declaring themselves the only arbiters of what constituted an appropriate question, they could avoid questions that might have led to challenges to their decisions. It seems, then, that although the doctors formally recognized both Brian’s and Lisa’s legal rights to informed consent, they defined those rights very narrowly.

In addition to expanding our understanding of how, whether intentionally or unintentionally, doctors can subvert informed consent, Brian’s story also suggests that, even if doctors value informed consent, achieving it will be difficult when family members have conflicting views. It is possible that with sufficient commitment and resources, hospital staff could have resolved the differences within the family, but it is equally likely that those differences were irreconcilable and the problems inevitable. The sources and consequences of such differences and the best ways for dealing with them remain as issues requiring further study.

At a broader level, this story demonstrates the continuing power and clinical autonomy of doctors in the USA. For more than a decade, sociologists have argued that bureaucratic, legal, and financial changes in US health care are threatening doctors’ professional dominance and clinical autonomy (McKinlay and Arches, 1985; McKinlay, 1988; Stoeckle, 1988; McKinlay and Stoeckle, 1989; Hafferty and McKinlay, 1993; Light, 1993). Yet none of these changes seems to have affected Brian’s care. The development of a bureaucracy specifically to monitor bioethics – the hospital ethics committee – had no impact on his medical care, probably because it was structured to respond to doctors’ needs, rather than those of patients or families. In addition, ethics committees are primarily staffed by doctors, while most other members are hospital employees. Professional loyalties, as well as the need to maintain good relations with colleagues, make it unrealistic to expect these individuals to view doctors’ actions critically (Bosk and Frader, 1988). Moreover, doing so might place their employer at legal risk, by providing grounds for a lawsuit by patient or family. Thus only the most foolish or selfless of individuals would do so. For the same reasons, the increased use of pastoral counselors and social workers to meet families’ psychosocial needs had no impact on Brian’s care. These individuals advocated for family members when they needed help with insurance forms and temporary housing, but advocated for the doctors when doctors and family came in conflict. Legal changes, too, which theoretically have given patients and families greater rights (Annas, 1989), had relatively little impact in Brian’s case; like most legal changes, changes in the area of ‘patients’ rights’ only have empowered unusually determined individuals with unusually good access to resources (Zussman, 1992). Finally, the financial constraints (such as ‘diagnostic-related groups’) that public and private insurers have imposed in recent years on US doctors (Dolenc and Dougherty, 1985; Dunn et al., 1988) have many loopholes. In Brian’s case, the most important loophole is that these financial constraints rarely apply in emergency situations.
(unless individuals reach the lifetime maximum that some insurers set for total covered medical costs); all Brian’s treatment—which totaled about $300,000—was covered by worker’s compensation, the state-run program that pays for treatment for occupational illnesses and disabilities. For all these reasons, then, we should expect to continue hearing stories like this one in future.

Notes
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1. All names in this article have been changed. None of the persons discussed in this article share my last name.

2. In any story like this one, it is difficult to balance ethical obligations to one’s profession against those to one’s family. I decided to write this article despite these difficulties both because I needed to do so, and because Lisa and her family wanted me to, as a way of giving some meaning to this tragedy through helping others understand the problems with informed consent in intensive care. I have left out some minor details of family dynamics that might hurt either individuals or relationships between individuals, but nothing that would substantially change the story.

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