

Mortality and medicine: forms of silence and of speech

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Silence can be harmful to patients, their loved ones, and doctors within the contexts of illness and bereavement. I draw from my experience with my son's illness and death to discuss five forms of silence—the silence around the experience of critical illness; the silence between life and death; the silence of doctors; the silence of the dead, and the silence of the ill—and of speech that may emerge in response to these silences.

Some time ago I wrote an essay inspired by a lack of contact from my son's doctors after his death on a paediatric intensive care unit. I wrote about how silence can destroy trust between surviving family members and doctors and can lead to lawsuits or the contemplation of lawsuits.¹ (The author has already told part of Jesse's story in *Medical Humanities*, as well as in other literature he mentions.²) After finishing that essay I reflected further on the theme of silence in regard to patients, family members or other loved ones, and doctors. Since my reflections here come by way of my experience with my son, I will start with him.

Jesse Harlan-Rowe was born in 1975. As an infant he had hydrocephalus, a condition in which the ventricles, spaces in the brain that produce and house cerebrospinal fluid and that cushion the brain from the otherwise violent motions of standing up, turning, and walking, do not drain off their excess fluid into the blood but, instead, become engorged. Symptoms of hydrocephalus include an enlarged head, lethargy, and vomiting. The standard treatment for this condition is a metal shunt through the skull at the back of the head connected to a tube, inserted under the skin, that drains excess fluid into the abdominal cavity. Without such treatment the head becomes even more enlarged as the swollen ventricles squeeze the brain, and the child may die at an early age.

Jesse had three operations for hydrocephalus in the first year and a half of his life and was in remission for the rest of it, although we, his parents, worried and watched and held our breaths during his annual check ups with his neurosurgeon. In 1991 Jesse was diagnosed with ulcerative colitis. In 1992 he was diagnosed with a mild case of sclerosing cholangitis, a scarring and narrowing of the bile ducts going into the liver. In 1993 an arteriogram performed before a forthcoming operation for colitis revealed early stage cirrhosis of the liver. In 1994 he was put on a waiting list for a liver transplant at a hospital in New York City, and in early May 1995 Jesse received his transplant. Four days later he was

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taken back into surgery with a fever and excruciating abdominal pain. His surgeons discovered a perforation in his intestine inadvertently caused during transplant surgery by the difficult task of cutting through adhesions, or scar tissue, that had built up after his colitis surgery two years earlier. Peritonitis had set in, to be followed swiftly by sepsis and multi-organ failure. To his doctor's amazement, Jesse rallied and received a second transplant, but another perforation, this time a result of his weakened condition, and another bout of sepsis, followed. He rallied again and there was talk of a third transplant until a sudden downturn, with another bout of sepsis, occurred. He died in August 1995 after a total of thirteen operations, including two liver transplants and a splenectomy.

Jesse was a talented artist. He worked with the rudest of equipment—a dull pencil and the blank side of a used sheet of typing paper—and under the most casual of conditions—sitting at the kitchen table, propping a few sheets of paper on his lap in bed, or sitting in a chair on our deck off the kitchen. He was quiet, but had a quick wit when he did talk and an amazing facility for instantaneously milking a phrase for any pun or double entendre it could possibly yield. And he had a shy vulnerability that moved many people to be protective of him. The flip side of this vulnerability was his refusal or inability, with rare exceptions, to talk about himself and his hopes and fears. But Jesse had a quiet strength, too, and a great courage that, I think, he hammered out in the furnace of a great fear about whether his body would carry him safely into adulthood. His loyalties to his friends and those he admired, including athletes whose bodies did not betray them, were fierce. And he had a high threshold for pain.³

My further thoughts about silence and modern medicine started with Jesse and his unruly body. There were Jesse's characteristic silence as an individual, the enforced silence of intubation and then tracheotomy during his 1995 hospitalisation, and the baffling metaphorical silences around certain aspects of his illness: why was his spleen so enlarged, well before he was listed for a liver transplant? Why was his portal hypertension so severe during the same period? His liver disease did not appear to be advanced enough to warrant either of these conditions. Then, too, Jesse's well earned reputation as a "poor informant" about his physical symptoms was both representative of his overall silence about himself and, at the same time, a complement to the silence, or mystery, of his body. There were other silences that frustrated you but compelled you to try to see through them, which hung like a vapour around Jesse. I want to draw

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from my experience with my son to illustrate forms of silence, both literal and metaphorical, that can cast a pall on patients, those close to them, and doctors, within the contexts of critical illness and bereavement. I also want to draw from my experience with Jesse to illustrate forms of speech, both literal and metaphorical, that may serve to partially dispel each of these silences.

FORMS OF SILENCE AND OF SPEECH

I will discuss five forms of silence: for family members or other loved ones, the silence around their experience of the patient's illness; for those same parties, the silence that inhabits the margins between life and death; the silence of doctors after the patient's death; the silence of the dead, and the silence of the ill. If the first three or four of these mainly concern family members and doctors and only the last one or two mainly concern patients, I see the interactions of family members and doctors as pointing toward, and ending in, the patient.

The silence around the experience

During the early days of Jesse's critical illness silence expressed itself, for me, as both a sanctification of his suffering and as something ineffable—there was a sense that I had been ushered, with him, into a strange and terrible world of which non-combatants knew nothing. This silence provided a kind of cocoon with which to smother negative thoughts, my own as well as those that might come from outside the concentric circles of sorrow—first the world of the hospital, then Jesse's doctors and nurses, and finally his parents and step-parents—of which Jesse was the irreducible centre. If writing is a form of speech that we make against silence, then for weeks I muffled my own voice, meticulously setting down in my "Jesse notebooks" the facts of blood drawn and given, blood pressure, temperature, the level of oxygen in his blood, and the bare clinical statements his doctors made during their rounds. Editorialising on my hopes or fears or commenting on the subtleties of Jesse's non-verbal speech—mostly hand squeezes and movements of his left leg—was out of bounds, for he lay on a hammock slung over the abyss and if we, his doctors and parents, could not pull him over into safe territory now, see him wake up and see his body (swollen with fluid seeping through his capillaries) shed the heaviness of disease, we hoped we could keep him from tearing through his hammock in his heavy waterlogged state. Thoughts or words, spoken or written, could upset this delicate balance, or so it seemed to me near the epicentre of this silence.

I did not breathe a word of this silence (of course not!) to anyone, even my wife, but I thought I shared it with her and with Jesse's mother and stepfather and even with his nurses and doctors. I supposed that Jesse knew and studied this silence, too, from an underground bunker deep inside his body, during the weeks when he was mostly semiconscious or unconscious. Outside the hospital, at the Transplant Living Center—a kind of mini Ronald McDonald house for the families of transplant recipients—I had to weigh my responses to questions our shelter mates asked about Jesse, lest their use of them in thoughts or off kilter prayers jinx him. Ninety miles away in New Haven on the one day during those three months when I made an appearance at work with the homeless outreach team of the Connecticut Mental Health Center, the silence that emanated unwittingly from my colleagues was more palpable. Only with one, a nurse who had cared for sick children and who had a son with cystic fibrosis, did I feel an unspoken communion.

It is clear to me, now, that the distance to the hospital from our home south of Waterbury and my work in New Haven—about an hour and a half in each case—helped to create this

silence and shaped my experience of Jesse's illness. Had he received his transplant at Yale-New Haven Hospital, the relative weight of life in and outside the hospital would have shifted somewhat for me. Seeing our two younger children most days, or having visits from friends and colleagues, or even holding occasional meetings with the outreach staff, might have broken the silence. Because of this, however, I must add that silence did not simply, or solely, do harm. The cocoon of suffering that enclosed me and, I think, others, was, after all, a cocoon. The sense I had, especially during those early days, of a horrible sacredness to Jesse's struggle protected me, too. My wife, Jesse's stepmother, went back and forth between hospital and home many times, was sucked into the whirlwind at the hospital and then went home to try to create a close to normal life for our two younger children, while I felt guilty about them in a fifteen minute phone call each day and then was sucked back into the whirlwind. Distance from work had similar advantages—I felt a bit guilty about the tasks I had left behind for the clinical director, but I would have felt guiltier, and more obliged to show up at work now and then, had Jesse been hospitalised in New Haven.

If the cocoon that encased me also protected me, this was, ultimately, a self defeating protection, since it imposed a silence both on me and between the world and me. But what to do about this silence? One incident gives a hint at a strategy that may help in cases like mine. Talking on the phone to Jesse's gastroenterologist, Dr Gardner,¹ in New Haven one afternoon during the first month of Jesse's hospitalisation, she said to me: "I don't know whether any of you writes, but there's a story to tell here". (I use pseudonyms for all medical personnel in this article). And so I began to think about telling Jesse's story, hoping, then, that it would end with his miraculous recovery. Now, since I am a writer, it is likely I would have found some way, or someone else, to give me permission to tell Jesse's story if I had not talked to Dr Gardner that day, but my point is that I was encouraged, even if unwittingly on Dr Gardner's part, to look to my own particular skills and interests for help, and doing so gave me strength to cope with a situation over which I had little control. Perhaps others might be encouraged to do what comes most naturally to them at a time when no response seems natural, for they are strangers in a strange land.

The silence between life and death

It was a cloudless late spring day. I was walking with my wife across a grassy field fringed with trees. Suddenly a creature covered with fur and moving on all fours yet somehow human, appeared and ran up to us. We were overcome with love for it. Others gathered around, drawn to our creature but also to us. The "oohs" and "aahs" of the crowd, the panting of the creature, which ran back and forth from onlooker to me to onlooker to my wife, made a looping music that enchanted us, so that we recognised too late the subtle changes it announced in the crowd's demeanour and physical aspect, from love to envy to hatred, from admirers to hunters. We had failed to protect our creature. It rose up in panic, now a butterfly. A pack of hound dogs bayed and leaped below it. It fluttered off kilter, fell down, turning into a flower, and became a spider. Its legs twisted crazily against the blades of grass.

"It's dead," my wife, or I, said.

"No, look! It's alive," I, or my wife, said.

"It's going to die. We should put it out of its misery."

"No, we can bring it back. We'll watch over it, and slowly it will turn into a flower, then a butterfly, then our creature."

"No, it's dead."

More than the sorrow I felt, more even than the wish to have back just a few moments in which all might yet be made

right if only we could open our eyes to the danger that must have been present from the beginning, was my sense of our powerlessness to do one thing or the other in our creature's defence. We had fiddled away its life debating whether it still possessed it.

We, Jesse's parents, did not fiddle away his life in debates about his chances. We did know the feeling of powerlessness, and tried to fight it by advocating for him with his doctors. Yet if we were amazed at Jesse's will to live during the weeks of critical illness after his first transplant and again after his second, I also wondered at times how long he could swing on his hammock slung over the abyss. I wondered, too, whether there was something simple, so simple, that all of us, doctors and parents, were missing, that would bring Jesse back if only we could find or remember it, and whether we were missing this thing not only because it was hard to find but because we, too, were trapped in the no man's land between life and death. I named this land Uncanada, the antithesis of Jesse's dreams, for he loved Canada madly, passionately, knew he would live there someday, though he never made it to within a hundred miles of its border.

Recently, reading Ronald Munson's new book on organ transplantation,⁴ I was surprised at the anxiety I felt over his discussion of cardiac death versus brain death and the enormous consequences, for those awaiting the gift of life, of the difference between the two. "My God," I thought, "in this post modern world we cannot have even life and death whole!" If the moment of death is uncertain, undetectable, and arbitrary, why then, simply reverse the old story of the athlete running halfway to the goal, then halfway from that point and halfway from that, never reaching the finish line, and you have death advancing into life, never quite overtaking it but becoming more and more indistinguishable from it. An illogical thought, perhaps, prompted by a logical fallacy, until you are plunged midstream into the illogic of disease. Closing Munson's book and pacing back and forth in our living room, I remembered my dream of the beautiful creature from so many years before, and thought of those days of dread in the hospital when sepsis struck and then struck again. The ghost of my dream, I suppose, may have played on me then and an unheard voice, I suppose, may have whispered in my ear, "If you, his father, can see this ghost, then what must the surgeons and intensivists, the residents and interns and x ray techs, even the nurses who fight to take care of him at shift assignment, what must they see?"

Still, strange land of critical illness that the hospital was for us, it was neither dream nor nightmare but what Munson aptly described as a "mundane and utterly alien" world of "terror mixed with boredom" that is a modern hospital and an intensive care unit. Fears we might let go of Jesse out of despair or exhaustion could not brush aside nineteen years of parenting or his doctors' years of training and their inculcation in the sacred art of healing the sick. So why give these thoughts their own numbered silence rather than include them with the first? Because the first involves holding on and the second involves letting go too soon, or not so much letting go as being unable to hold on. But what speech can dispel this silence? Only the speech that reminds us of what we claim to be. For parents, this speech reminds us that the work of love is the hardest work of all, since it gives no quarter to sentiment nor a free ride based on past performance. For doctors it is a reminder that life on an intensive care unit is a thing of tiny balances, that medical ethics and principles, institutional standards and practices, cannot protect them from the frustration of one step forward, two steps back, and that they need not relax their hold much to lose their grip on one who is being dragged off by main force.⁵

The silence of doctors

Between my wife and me and my ex-wife and her husband, one or more and most often two or three of us were with Jesse every day of his hospitalisation and during many long nights. We grew close to several of his doctors (as well as many of his nurses). I felt a special closeness to Jesse's chief surgeon, Dr Dorand. He had met Jesse at the liver clinic before his hospitalisation and reached out to him, talking about how a liver transplant could help him move forward in his life. There was a vulnerability to Dr Dorand's style—a social awkwardness and some physical tics—that I thought went well with Jesse's own social awkwardness and vulnerability. And Dr Dorand had a way of putting an optimistic spin on an avalanche of bad news. If Jesse had a fever, at least his body could mount one. If almost all his liver numbers were going in the wrong direction, one of them, arguably, was going in the right one. I persuaded myself that Dr Dorand's optimism was a function not only of personality and a desperate wish to avoid having a patient die on his watch, but also of a special feeling he had for Jesse. One afternoon, braving ridicule for a loss of objectivity, he walked onto the unit carrying a guitar case, past the nurses' station and into Jesse's room, took out the guitar, and sang and played for him.

After Jesse died, there was no question in my mind that Dr Dorand was going to call us, until several days and then weeks passed and he did not. Eventually, my wife and I did meet with him to discuss his proposed leadership of a group of hospital staff and family members that would draft bereavement policies for the liver team. After that meeting, though, another long silence ensued. Over time, lack of contact from Jesse's doctors appeared to us, first, as insensitivity, then as a betrayal of our trust in them, and finally as a cover up. Three months after Jesse's death I took a train into New York City and spent the day in the medical records office of the hospital, thus beginning a nine month investigation into whether malpractice had occurred. (My investigation ended with my attorney's decision that, though there was merit to the case, malpractice would be hard to prove.³)

I realise, in retrospect, that my expectations were too high. I was encased in the cocoon of my grief; Dr Dorand was trying to save other lives. I was fixed, standing in place; Dr Dorand had moved on to the next crisis. And how difficult it must have been for him to talk to, or even think about, the parents of a child who had died under his care! Still, high expectations or not, I think Dr Dorand and Jesse's other doctors could have done better, and I think part of the reason they did not, and that others may not under similar circumstances, is the low expectations we have of them. During the first few months after Jesse's death, I talked to friends and associates about my frustration and anger. Often, I would hear comments along the lines of: "Doctors deal with death so often they would burn out if they had to talk to parents". Now, setting aside the fact that such an argument ignores the moral issue of whether contact should be made anyway, the legal issue that silence may lead to lawsuits, and the question of how the medical profession might be able to help its own when it comes to dealing with patients' deaths, the notion that doctors have a good reason—concern for their own professional survival—to avoid talking to the bereaved, seems to me to be a defensible point. Yet while I am not aware of any research on this subject, common sense tells me it is just as reasonable to suppose that doctors are harmed by not talking to family members, by shutting up their feelings and going on to the next case and the next crisis.

I do not say there are easy solutions to this problem or that doctors need only follow rules of thumb such as: "Talk to family members after your patients' deaths," or "Go to your patients' funerals," or "Send a note to the parents" Professor

Munson used these phrases in an e-mail to me on 13 October, 2002. What is right for one family may not be right for another. But we human beings tend to find ways to respond to the problems we take most seriously. Training of residents, the role modelling of senior physicians who practise the art of empathy,⁶ and the concept of medical forgiveness, involving laws that allow doctors to say “I am sorry” without being sued for having uttered those words,^{7,8} may all be fruitful approaches. Respect and attention for these issues as worth pursuing are the first order of business. Creative ideas and strategies will follow, and bereaved individuals and families might even be partners in this process.

The silence of the dead

The dead cannot speak for themselves, or to the living, who may feel called upon to speak for them in order to break a silence that seems to envelop the dead for the world at large. After Jesse’s death, the idea of “witnessing” his struggle impressed itself upon me, as did the idea of “representing” him to the living. If, as I have come to believe, advocating for a patient during his illness involves representation in two senses: that of *representing* the patient, advocating for him and acting in his stead, and that of providing alternative *representations* of the critically ill patient lying on his bed (we taped photos of Jesse next to his liver chart on the door to his room—for example),⁹ then representation may also occur after the patient’s death and be part of the act of witnessing.

The decision to witness another’s suffering carries with it the dangers of arrogance and error. What would one’s subject say? How would he want himself to be represented? Would he ask for silence from others because (as in Jesse’s case) it is not in his nature to talk about himself, or because he fears that those he cares about most will be hurt by someone else’s speech? We cannot know “the irreducible secrecy of suffering”¹⁰ that was another’s on the way to his death. We must admit, then, that we cannot tell another’s story as he would have told it. For whom, then, do we speak when we speak of the dead?

It is tempting, given qualms of conscience that tell us we may become imperialist overlords of the dead in our professed need to represent them, to say we cannot speak for them but only for ourselves and the living, who may learn from our experience. Yet I think there is a place for witnessing in the sense of Alan Merriam’s definition of witnessing, namely “to be with and for” those whose suffering and occasional triumphs we try to put into words. (Dr Merriam, retired chaplain and Clinical Professor of Pediatrics at the Yale School of Medicine, gave this definition during his presentation, “The Plague in Literature and Medicine”, for the Faculty of Bioethics Workshop at the Yale Institution for Social and Policy Studies, on 10 February 2000.) Starting with humility and with the conviction that a spell of silence must be broken, we can speak in our own voices for the sake of the dead, living on the cusp of a dilemma whose two prongs are: “How can I speak for another who can only speak for himself,” and: “If I, who knew him so well, do not speak for him, then who will speak,” as opposed to keeping our own counsel because we might err.

The silence of the ill

Many ill or profoundly disabled persons—the actor Christopher Reeve comes to mind among the latter group—can speak eloquently for themselves and require no stand in. Others, though, cannot make their claims so well, or not in the forms of speech or writing, each of which has a special status in our society. If I may offer an analogy between those that dwell in the land of the ill and those, like persons who are homeless, who dwell at the margins of society, I have tried in my research with the latter group to give space for individuals to speak for themselves.¹⁰ Like other ethnographers,

though, I have found that when you interview fifty people you end by relying on, quoting, and drawing your conclusions from the eloquence of half a dozen of them. It is the articulate who found their way into my pages on homelessness, the articulate to whom I gave space for their voices. Did they speak for the others? Better than I, perhaps, but did their very ability to express themselves render their experience qualitatively different from that of their compatriots?

It may seem contradictory to try to give voice to the silent, but we should take care lest our judgment reveal itself to be our own need or our inability to “hear” their particular speech. Michel Bérubé notes that “[v]isual representations are language, too, which is why we can ‘read’ them”.¹¹ Writing about his son, Jamie, who has Down’s syndrome, he gives examples of other individuals with Down’s syndrome who are speaking in their own voices about who they are and what they want for themselves. He concludes by saying he has an obligation to speak for his son now, “to set his place at our collective table”, (Bérubé,¹¹ p 264) but that, in doing so, he hopes to set the stage for the day when his son will make his own claim in his own voice. My son spoke most eloquently in his drawings of mythic heroes and caricatures of vulnerable persons which, I believe, reveal his feelings about his own struggle. In the hospital, though, after the first four days, Jesse was not only reluctant to speak in the conventional sense but physically unable to do so, first because he had a breathing tube in his mouth and later because he had a tracheotomy. With the tracheotomy he could mouth words, but we were only middling lip readers. Then again, on the many days, especially during the last half of his hospitalisation, when he was not unconscious from illness or sedation his hands shook and he was too weak to draw. During these times, he spoke in gestures—a hand squeeze, a smile or frown or arched eyebrow, a hand pointing us back to our seats when he had had his fill of our ministrations. We witnessed his eloquence in his relationships with his nurses and doctors and with us.

There was his day nurse, Brooklyn Ellie, who infuriated me and, I know from the ice in his eyes, Jesse, on day four after his first transplant when, getting him ready to go back into surgery, she said: “Don’t wawwry Jesse, they take you baaack and baaack and baaack”. Who could have guessed that, before the end, the two of them would have worked out a private language of eyes and winks and the slightest movement of hand, and that Jesse would speak to her with nods and half smiles and little ways of helping her bathe him or turn him on one side, then the other, to change his sheets?

There was Jesse stretching out his hand to Dr Dorand on a bleak day when it must have cost him much to do so, waiting until Dr Dorand took a step forward and offered his own hand, then nodding at him and smiling as if to say: “Yes, you’ve done well”.

And there was the afternoon a week before his final bout with sepsis when Jesse turned toward me and mouthed some words. I came up to the side of his bed. He mouthed again. “I love you,” I thought he said, but I was afraid to say “I love you too”. It was so frustrating for him when we misread his lips! I squeezed his hand and lowered my head. He nodded, yes, and drifted off to sleep.³

Looking back on those days, I treasure the moments of silent understanding.

CONCLUSION

The silences of critical illness may instruct or challenge, lull or oppress us. At times we must respond to them with speech, though not with the illusion that healthy speech dismisses ill silence any more than the power of positive thinking dismisses tragedy. My reflections here assume the right and, sometimes, the responsibility of family members

and others to witness for their living and their dead, and a measure of responsibility, on the part of doctors, to attend to the silence that hovers about critically ill patients while they fight for their lives, and to grieve with their survivors if they die. Even if doctors have no such duty to non-patients, grief refers back to the patient who, their survivors hope, is not simply dead but lives on in their memories and even, a little bit, in those of others. As for those who are ill, let them speak for themselves when they can, let us try to ensure that those with their best interests at heart will speak for them when they cannot, and let us listen and look for the forms of their speech that, perchance, we will not easily hear.

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