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Tethered to the Diving Bell: Beyond Vulnerability to Autonomy

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Respecting the autonomy of patients is complex and subtle. First and foremost, patients with serious and disabling illnesses experience *dependence* because their ability to express themselves is compromised in some way. They are vulnerable and need help. *The Diving Bell and the Butterfly* by Jean-Dominique Bauby tells the dramatic true story of a man living with locked-in-syndrome (LIS). His motionless body belies his desire to interact with others. As Bauby's memoir richly describes, autonomy is not simply a matter of having a will of one's own; it depends on our ability to communicate with others and on others' willingness to listen and connect with us. Because it was virtually impossible to tell what Bauby was feeling or thinking, caregivers had to find a way into his diving bell. They did this first by diagnosing and treating him, and second by finding ways to help Bauby express himself. By paying attention to his vulnerability, they helped restore his autonomy. When internal medicine residents and I discuss the memoir, we notice the intricacies, surprises, and challenges of respecting patient autonomy. The residents also empathize with the isolation experienced by seriously ill patients, which can lead to more compassionate care.

In *The Diving Bell and the Butterfly*, Bauby describes his experience of being locked in. The English translators chose "diving bell" over "diving suit" for *Le Scaphandre et le Papillon*, an apt metaphor for his experience of feeling like a prisoner. Used as a base for divers, a diving bell is an airtight underwater chamber suspended by a cable. The fate of the divers rests in the hands of the surface crew who ensure pressurized and breathable air is pumped into the bell. Bauby is, at times, autonomous. He is also profoundly vulnerable. For physicians who respect him, autonomy and vulnerability are bundled together. Medical caregivers control the breathable air entering the "diving bell," and Bauby is tethered to them, not only for his life but for his identity.

After recovering from the trauma of a pontine stroke, Bauby could rightly be described as autonomous. Though sounds were distorted, he could hear, had the use of one eye, and could swivel his head, but was otherwise expressionless and inert. He had decision-making capacity and through painstaking effort could make his wishes known. Bauby could be entrusted to know what was best for him. Still, he needed others to help him convey his wishes and values. A major goal of his treatment for LIS was to help him regain his autonomy and to give him new tools for asserting himself. His memoir is a testimony to the irony of autonomy: the way to respect autonomy is often to pay vulnerability its due.

Autonomy can be interpreted in psychological as well as ethical terms. People need the psychological and cognitive ability to choose their life plans freely and act on them independently [1]. Due to our inescapable reliance on others, no one is fully autonomous, but each person self-legislates in varying degrees and scope. Those with a sufficient degree of autonomy—individuals who are largely in charge of their lives and decisions—are called substantially autonomous persons [1]. Even those without fully realized autonomy retain capacity to make some meaningful choices. The preferences of children and cognitively impaired patients matter, even when a surrogate is needed. Ethically, we respect autonomy when we allow health care decisions to be guided by the patient’s particular values, worldviews, and life plans. Respect for autonomy is a corrective to paternalism, which presumes doctors have the authority to decide what is best even for substantially autonomous patients.

Through diagnosis and treatment, doctors shape Bauby’s identity and support his autonomy. His friends report the exchange of gossipers at a Paris cafe. “Did you know that Bauby is now a total vegetable?” “The tone of voice,” Bauby observes, “left no doubt that henceforth I belonged on the vegetable stall and not to the human race....Instead I would have to rely on myself if I wanted to prove that my IQ was still higher than a turnip’s” [2]. Bauby was “in there,” but to find him, caregivers had to reach in through the placid facade to the man inside. Waiting for some assertion of autonomy would have been disrespectful of him. So what did they do? They encroached upon his isolation and interpreted his silent cries.

The lifeline into Bauby’s diving bell was the communication system invented by his speech therapist. Visitors read letters of the alphabet to him in the order of the frequency of their occurrence in the French language, and Bauby blinked when the letter he wanted was read aloud. Hours were devoted to crafting and memorizing the chapters of his memoir, which was dictated letter-by-letter. The system was used by most of his friends but only two hospital employees.

So I usually have the skimpiest arsenal of facial expressions, winks, and nods to ask people to shut the door, loosen a faucet, lower the volume on the TV, or fluff up a pillow. I do not succeed every time. As the weeks go by, this forced solitude has allowed me to acquire a certain stoicism and to realize that the hospital staff are of two kinds: the majority, who would not dream of leaving the room without first attempting to decipher my SOS messages; and the less conscientious minority, who make their getaway pretending not to notice my distress signals [3].

His description makes us wonder why so few members of the care team learned his communication system. Perhaps questions were posed by physicians, and the speech therapist, with the luxury of time, helped Bauby answer. Perhaps some found ways to discuss many subjects via Bauby’s SOS signals, but any physician who tried to learn the system and patiently waited for a specific response demonstrated unquestionable respect for Bauby’s autonomy. One of the great dilemmas of his new existence was the forced absence of repartee. As awkward and laborious as

communicating with him must have been, it is excruciating to imagine Bauby's perspective—having a quick response on the tip of his tongue without the ability to command speech. *The Diving Bell and the Butterfly* reminds us that what we owe patients is not respect for autonomy *per se*, but respect for persons, which always involves delicately balancing autonomy and vulnerability.

While describing the slow awakening to his new life of grave disability, Bauby rarely rages against medical staff or indulges in self-pity. When I discuss this memoir with internal medicine residents, we always talk about the following passage.

I have known gentler awakenings. When I came to that late-January morning, the hospital ophthalmologist was leaning over me and sewing my right eyelid shut with a needle and thread, just as if he were darning a sock....What if this man got carried away and sewed up my left eye as well...the one tiny opening of my diving bell [4]?

Despite frantic blinking to summon the doctor's attention, Bauby concludes, "Disinclined to chat with normal patients, he turned thoroughly evasive in dealing with ghosts of my ilk, apparently incapable of finding words to offer the slightest explanation" [5]. If caregivers are the lifeline to Bauby's diving bell, then this doctor was certainly suffocating him.

The residents and I wonder aloud about the ophthalmologist's perspective. How might he have described the experience? We recognize that sometimes physicians must focus primarily on the task at hand, not the patient's experience of it. Residents also recognize the apathy and numbness that is a precursor to burn-out. When a physician desperately needs to rescue himself, it can be difficult to muster sympathy even for the most vulnerable of patients. Perhaps this physician and Bauby *shared* the experience of isolation [6]. While the physician's suffering and isolation is vastly different than Bauby's, the memoir allows us to discuss how residency can feel like being trapped in a diving bell. Overworked residents sometimes feel like they have been stripped of their identity, executing the judgments of attending physicians with whom they may or may not agree. Here, too, the solution is to recognize and pay respect to one's vulnerability—to reach out for help and to let colleagues reach in and pull you out of isolation.

Respect for autonomy is important, because competent patients only feel respected if their individual desires and preferences are taken into account. Bauby had to reinvent himself and mourn the loss of his pre-stroke self [7]. The memoir moves between vivid descriptions of the man he used to be, his imagination (both butterflies), and the diving bell of LIS. Respecting his autonomy meant riding waves of indecision, contradictory preferences, and loss of identity as he settled into a life no one would choose. "I have begun a new life, and that life is here in the bed, that wheelchair, and these corridors. Nowhere else" [8]. It meant searching for the animated mind trapped in a motionless body. Those who attended to his vulnerability *first* guided him as he

groped toward the substantially autonomous person he knew himself to be or had to create because his illness had changed him. Sometimes this breath of fresh air is as important as the medical treatment, because it gives patients the will to keep searching for and reinventing themselves.

References

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