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"Hear me!"

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Abstract

I am respectfully submitting a narrative essay to this journal. As a faculty member at a residency program, I got interested in contributing this essay after my experience caring for a disabled patient. I presumed we tend to imperfectly decipher what our patients' needs are and my experience highlighted the need to be more sensitive and less dismissive to patients with disabilities. I started with the assumption that there were minimal teaching points to the house staff since this was an overt outpatient placement case. I was wrong and learnt much more than I expected. As faculty physicians, we tend to highlight pertinent clinical data to the learners and inadvertently gloss over vital nonclinical details that ultimately are as important. This patient was very succinct with her demands and understandably upset with our blatant conjectures with our daily mundane clinical rounds and consults. Taking time to listen to her, having a team meeting in her room and coordinating her care with nursing and medical colleagues was not only a learning experience but made me a better physician and teacher. She was the focus and her needs were met, not ours. I have no financial conflict of interest, and the patient was aware I intended to share my experience with my peers. I will appreciate any feedback and opportunity to learn and improve this narrative with expected revisions.

Keywords

clinician-patient relationship, medical decision making, patient expectations, patient perspectives/narratives, patient satisfaction, team communication

"Hear me!"

While on the Hospitalist service, I met Chloe, a 43-year-old woman with quadriplegia transferred from the medical intensive care unit after an unsuccessful suicide attempt with an intentional medication overdose. She was presented to our day team at sign out. Her medical history was notable for cerebral palsy, quadriplegia, neurogenic bladder, depression, and post-traumatic stress disorder. After few seconds of assimilating this information, we looked around perplexed; wondering why and how a quadriplegic will do that. Cautiously, we perused her medical records hoping to get some clarity before rounding on her.

She was part of a unique program called the Complex care consult service. This program cared for adults with various disabilities like Chloe and encouraged functional independence, with support from a multidisciplinary team consisting of home health aides, personal care assistants, social workers, occupational and physical therapists, and psychiatric providers headed by a nurse practitioner (NP). As a result, with adequate support and close follow-up from their health care team, these individuals were rarely admitted and when this happened, they are discharged home in a timely fashion after their acute ailments were addressed. In fact, this was Chloe's second admission on record.

Chloe lived at home with 2 assistants, each with 8 hours daily. She also had a twice weekly home check with her NP and behavioral worker. She was highly educated and fiercely independent. She had an electric wheelchair with lots of adaptive gadgets including a laptop with voice-assisted capabilities. She was found at home the evening prior with a suicide note, a homemade Do Not Resuscitate notice, crushed pills with a modified cup and straw on the electric chair table. Emergency medical service responded to the call by her night aide and found her pale, diaphoretic, hypotensive, somnolent but coherent. The ED pharmacist was able to identify pill fragments of tizanidine and hydrocodone–acetaminophen combo. N-acetylcysteine (NAC) protocol was initiated, and she was transferred to the medical intensive care unit after an endotracheal intubation to protect her airway. She was extubated the next day and transferred to our

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service for the team to coordinate outpatient psychiatric placement.

She was medically cleared for placement, but her extensive personal care needs exceeded the requirements acceptable in local psychiatric residential facilities. In any case, we were entranced by what triggered this drastic decision. I chose to introduce myself and met with her without the house staff team due to the sensitivity surrounding her admission. She was in her electric chair, watching a movie and suspiciously tracking me. After a quick introduction, she echoed our concerns for her admission, disposition and startled me with this assertion: "I did it because no one listens to me. I have a mouth in this imprisoned body of mine and I intend to use it!"

Speechless and stunned, I quickly figured this was not going to be a rushed visit, I sat down. She informed me that she lived in a "disability-unfriendly" housing and it was limiting her independence. The elevator was frequently nonfunctioning and her multiple attempts to advocate for more adaptive changes in the building like having her door control voice activated fell on deaf ears. She sensed her care was complex but appreciated her assistants, her NP, and the behavioral support staff. She was compliant with her medications, but she was tired of being labeled "that difficult one" by her team just because she had strong sentiments about her needs and her care.

Since her MICU transfer to the medical floor, she was annoyed with her room assignment. She demanded her room be close to the nurses' workstation knowing her constraint with calling for help in a timely fashion. She begrudged the 1:1 sitter in the room who spent more time on Sudoku puzzles instead of engaging her. She resented the large teams of multi-specialties rounding daily on her without actually "talking to me" but instead deliberating as if she was mentally incompetent. She questioned the utility of the inpatient gynecology consult regarding an overdue intrauterine device change trumping her acute psychiatric distress.

Essentially, she concluded, she was mindful of her needs, and she wanted to be engaged in decisions regarding her care. Trying to find out how the overdose incident happened knowing she may have had some assistance was futile. She declined to elaborate but admitted she had some help. Sitting with her and letting her vent was also a learning experience for me. For one, I was one the "decision makers" lumped in with my peers rounding on her and planning her disposition. As the admitting attending on service, I empathized with her and assured her I was going to get her views made known to the nursing and medical team and see how best we could ameliorate her stay.

The nursing team moved her closer to the workstation and worked with the clinical engineering department and occupational therapy to offer more adaptive gadgets. Her medications were tweaked and seemed to help. She accepted limits to daytime vitals, increased reading materials and visiting time with friends. The nursing team promoted staff consistency with assignments.

We scheduled a team meeting in her room with her outpatient behavioral team, NP, our inpatient psychiatry rounders, and case management. Her transfer to a psychiatric residential unit was nixed and the psychiatrists deemed her chronically depressed but with low imminent risk of suicide. We all agreed she will thrive better at home with more community and intense mental health support. Her discharge planning recommendations included immediately discontinuing her sitter and setting up a home safety assessment. Medication dispensing from a metered locked box supervised by her NP and nurses was approved. The case managers got her approved for 24-hour PCA care coverage, scheduled transportation to outpatient follow-up, and subsidized passes to local museums and diverse outdoor activities. Her outpatient behavioral team was planning to continue structured and supportive care and work with the building authority to enhance her safety and make the building more disabled friendly.

A week later, Chloe was sent home appreciative of her discharge plan. This exemplifies that actively listening to our patients fosters healing and trust. Chloe was heard!

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