

Jennifer Repper-DeLisi and Susan M. Kilroy, “‘We Need to Meet’,” *The Journal of Clinical Ethics* 17, no. 1 (Spring 2006): 85-9.

## “We Need to Meet”

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More than four months into Lorraine’s admission, the call from the unit had become a familiar one: “We need to meet.” We had many meetings about many things: Lorraine’s refusal of treatments, her abusive language, the weekend she threw her food tray, her demands to see the physician who was on call during the night. This time, at least one of the problems was that staff members were not sure how to deal with a patient who had been caught trying to inject herself with hoarded pain medication. It was one of many issues to be addressed in the care of a very complicated woman whose struggles seeped into every possible domain.

Our meeting of the minds included a physician (Robin Dauterive), nurse practitioner (Grace Good), case manager (Suzanne M. Burke), the clinical nurse specialist on Lorraine’s unit (Susan M. Kilroy), a psychiatric nurse consultant (Jennifer Repper-DeLisi), several specialists, and staff nurses. There were 31 people at such meetings of Lorraine’s care team. By the end of this meeting, everyone had had a say, and a two-page document of problems and proposed interventions was the result. In spite of the general frustration, there was the familiar infusion of concern and care as we communicated on the interventions necessary to maintain Lorraine’s safety and security as a patient on the unit.

We had come a long way from the early days of Lorraine’s admission, when she took the unit by storm. “She’s moving in,” we thought, when she showed up with what appeared to be a large proportion of her belongings from home, including clothes and a collection of dolls. Because of her care needs, she was moved into a single room. Then she sent the staff reeling as she persisted in chasing us out of the room. The chase was sometimes a literal “Get out!” Other times it was in her commands, threats, swearing, and, from the beginning, her refusal to accept our care. Her refusals were evenly matched by her unremitting requests and demands. Molly, her primary nurse, remembers, “It was like she had arrived with her own agenda, and what all of us wanted to do for her was completely different than what she had in mind.”

Jennie (the first author of this article) recalls that when she was first called to see Lorraine early in her admission, she hoped she wouldn’t be there too long. While Jennie knew that the staff were skilled in dealing with many of the psychiatric concerns of their patients, Lorraine’s capacity to intimidate, to engage staff in destructive conversations about their peers, to criticize every aspect of her care, was formidable. Her primary nurse, Molly, described her first meeting: “The room was pitch black. It was a very, very dark space, a dark cave. She was a ‘Being’ in this bed who would boss you around. I knew what she had put others through. I was very intimidated by her.” Many of her nurses were novices in the profession. As one new nurse put it, “She knew enough about her own care needs that she often tried to use her knowledge and

experiences to intimidate, compelling me to frequently check and recheck my skills and knowledge level."

We have seen that patients with personality disorders have a tendency to divide staff and to lead them to feel demoralized and burned out in their efforts to provide care that is never "good enough." Molly highlighted this experience when, after a series of particularly grueling days, she said, "I don't like myself in the room." Lorraine had burned many bridges with healthcare agencies. We knew that the nurses on White 10 could be added to a long list.

We believed that frequent interdisciplinary huddles, with the understanding that one person's need to meet was everyone's need to meet, were essential to help both Lorraine and the staff rise above the natural responses of frustration, anger, and rejection. Meetings were a time to share ideas, bolster one another, discuss, and plan. Team cohesion became the glue of Lorraine's care. As Molly put it, "You got that extra emotional support from everyone else. Each day there was someone to ask how she was doing. There was always an outlet or a pow-wow." Additionally, we needed to give staff the interpersonal tools not only to help them survive eight hours of caring for Lorraine, but also to work productively toward a favorable outcome for her. Courtney, another nurse, said, "We had to stay checked in. We didn't have the choice to check out."

Our priorities became, first, how to help the staff stick together; second, how to balance hope for change and participation in Lorraine's care with an acceptance of her limitations; and third, how to foster therapeutic communication between Lorraine and the people taking care of her.

Caring for the nurse who was assigned to Lorraine for an eight-to-12-hour shift was our top priority. If the nurse didn't feel supported, Lorraine's care would be compromised. Primary nursing was next to impossible. No single nurse felt able to manage the burden of Lorraine's care day after day with unending responsibility for leading the nursing team. Taking care of Lorraine on an everyday basis was just too draining. Staff nurses were overwhelmed. Many reported thinking about her outside of work. Others dreamed about her.

Sue, a clinical nurse specialist and the second author of this article, knew it was crucial for the patient to have consistency among those planning and providing her daily care. Besides, our unit is small; most of the staff knew Lorraine. We agreed to rotate nurses, giving each nurse the opportunity to decide how long she or he could care for her. For instance, a certain nurse might be able to care for her for three days in a row, if Lorraine was in control of herself. Another nurse would need a break after one difficult 12-hour shift. We felt committed to the notion that staff would feel free to let us and each other know their limits. As a group, the staff felt a greater sense of control over their practice and confident in a consistent approach.

Caring for Lorraine required a thoughtful flexibility. Going where the "Lorraine wind" blew was wearing and counter-therapeutic. But our efforts at holding rigidly to rules were ineffective as well. Developing reasonable expectations that accounted for Lorraine's maneuvers and changing capacities was an ongoing challenge that required a great deal of dialogue and "processing." There was almost a daily search to find the balance between a nurse's personal capacities and what was necessary to provide care to Lorraine.

Staff were vulnerable when they were in Lorraine's room, and she knew how to "get" to them. She was a master at "pushing buttons." Staff needed to learn how to preserve themselves and defuse the tension created by Lorraine's anger. Providing scripts for the most common and tension-producing situations helped staff to have a sense of control and to "get back in the driver's seat."

It became easier for staff to leave anger at the door if they entered the room with some tools to manage Lorraine's behavior. They began to provide her with constructive feedback, limiting their response to those behaviors that she used to push others away: "Lorraine, I can't be with you when you're calling me names. I'll come back in 10 minutes." They also made clear what behaviors could not go on and set reasonable consequences. For example, smoking in her room led to taking away her cigarettes and calling security for a room search. Eventually nurses were able to let Lorraine know when she was pushing the limits of what they could offer. Courtney remembers, "When she was found crushing her meds, a lot of us who had gotten close to her felt betrayed. When I first heard about it, I went into her room and let her know how disappointed I was in her."

Probably the most trying and anxiety-provoking aspect of Lorraine's care was pain management. With Lorraine, pain was a sticky subject. We knew from her primary care physician in the community that Lorraine had trouble resisting the temptation to overmedicate herself. This had been an out-patient concern for a long time. But now she wanted to overmedicate herself with our assistance. As nurses, we're taught that pain is pain and needs to be treated; but no matter what Lorraine was given, it was never enough. She would open her eyes in a sedated state and demand more. As a result, it was no surprise that nurses would often return with medication to find Lorraine sound asleep. Nurses became very uncomfortable at the thought of administering large doses of narcotics to someone with slurred speech and somnolence. When blood pressure and oxygen saturation parameters for giving pain medications were set, Lorraine would purposefully hyperventilate in an attempt to meet the requirements. Nurses were perpetually worrying that giving narcotics would further depress her mental and respiratory status. Yet if the nurse did not give Lorraine pain medication because she was asleep or had depressed vital signs, she reacted badly.

Nurses faced this quandary on a daily basis. What was Lorraine's physical pain and what was the pain of her addiction? With multiple narcotics ordered, both standing and as needed, and with Lorraine's constant requests for more, were we just reinforcing her addictive behaviors? According to Molly, the ethical dilemma became, "Am I medicating her because she's in pain, or am I medicating her to get her out of my hair?" The pain team had begun following Lorraine. Jennie hoped that the pain team would take on a decision-making role about Lorraine's pain medications to take something substantial off the nurses' very full plate. The day that Dr. Acguardro agreed to take on the decision making, ordering, and to be the "bad guy" with Lorraine was a day of enormous relief for the nursing staff.

These new boundaries around managing Lorraine's pain and her demands for medications seemed much more therapeutic for her and made it possible for us to work effectively in concert.

Then, about three months into her hospital stay, Lorraine decided to let herself die. No antibiotics for infection. No more efforts to heal her huge decubitus wound. Medically, there was hope for Lorraine, but she was choosing a path that would lead to her death. Found competent by the psychiatrists, the choice was left in her hands. She was an adult, capable of making her own decisions, not actively suicidal, so she had to be allowed to make bad choices if she so desired, so long as she was informed of the risks. We were taken aback by this. Here we have this feisty woman who has struggled with us every step of the way. Although she was locking horns, she was engaged. Once again, she had pulled the rug out from under our feet. We felt shocked, confused, angry, sad. What should we do? Did she really mean this? Or was this just more acting-out behavior? All of us were disquieted. Were we going to just watch her die?

Initially, caring for Lorraine in this context increased the general stress of the staff. Not only were they struggling with the interpersonal stress of caring for her day after day, they were now in the position of dealing with additional ethical concerns and obligations. Should we try to change her mind? Do the doses of pain medications still matter? In our experience, sick patients came to the hospital for care. Those patients whose illness was not treatable went to hospice, or sometimes died on the unit. But they died because there were no other options. And usually they were older than Lorraine. They didn't die when there were successful treatment options available.

As a psychiatric nurse, Jennie struggled along with the staff through this crossroad in Lorraine's care. The chronicity of her dysphoria and wish to die were not acute, but were an underlying factor. No, she was not "actively" suicidal, did not have a plan or imminent intent, but she had expressed a long-standing wish to die and had at least one past suicide attempt. Were we aiding in her suicide? The legal response seemed clear after many psychiatric consultations and multiple team discussions — Lorraine has the right to refuse treatment even if her refusal results in her death — but the ethical one did not. Besides respecting Lorraine's right to decide, what constituted beneficent, faithful, and fair caring for Lorraine?

Then she didn't die, not for a very long time. We all waited for infection to overtake her, then stood back in amazement as Lorraine's own body fought her choice. Her hopelessness was clear when she said, "I can't even do this right." We had thought that she would quickly become septic and die. Now what? This added to the ambivalence and distress we all felt. When she periodically decided to have labs drawn, and at one point

requested a blood transfusion, this added to the angst. Was she trying to slow the process down? Did she not want to die? As we approached the winter, she wanted to go shopping for a new winter coat. That was definitely a mixed message. Our big question was: is this the "normal" ambivalence that anyone would experience while dying, or was this Lorraine's way of doing this, or was she trying to tell us she didn't want to die? We continued to be uncomfortable, and we would meet to talk and to think about what exactly we should do on any given day.

The scope of Lorraine's care would have to be broadened, we thought, beyond what we usually provide in an acute-care setting. First, we tried to accept her decision to die, and to accept that she would not be leaving the hospital until she had died. We needed to transition from a position of vigorously trying to help Lorraine accept care and recover, to one where we would now see her through dying to her death. We had to help the staff take a more hospice-like approach — which meant a substantive change in values — to help Lorraine have a dignified and comfortable end to her life.

Nurses banded together to share the responsibility of caring consistently for Lorraine. This woman who had difficulty making positive relationships now found herself surrounded by individuals willing to care for her. A transformation occurred. For the first time, we all, Lorraine included, agreed on a plan of care. This was a bit of a turning point. Most of the struggle was gone. We could focus on providing Lorraine with what she needed without arguing about it. Several nurses took the time to search for the inroad, to find common ground. Interactions became more relaxed. Staff found they could "chat" with Lorraine about music, or about her children, or clothes. They could let her talk about her life. While it was still critical for staff to support and care for those who were doing the difficult work of caring for Lorraine, this new goal enabled staff to rally, to re-engage, and to help Lorraine in a way she experienced as caring at least some of the time. In this way the nurses were able to build relationships with a patient who was skilled at chasing people away.

The one point we continued to have some difficulty around was Lorraine's dressing changes. She often refused the changes or wanted to put them off. The dressings became saturated and foul smelling. So a compromise was reached: nurses figured out a way to change the dressing as quickly as possible, with a minimal amount of turning. So it essentially became a win-win situation.

Courtney said, "I got a picture of what her life had been like, anguish, heartache, and disappointment. She had this yearning in her eyes for someone to really like her. But she was really scared to have someone like her. Some days I would go home and rip my hair out, but I was finally able to develop a trust with her." Courtney repeatedly questioned her own caring. "It's my job to take care of you, and I get paid to come and take care of you. It's my job to care. How much do I care as a person, and how much do I care because I'm here? It was confusing to me. But I knew I cared about how I affected her, especially when I knew she was benefiting."

Molly said, "I opened my eyes to the fact that she wasn't just a patient, she was a person. I would almost hate to care for her some days, but she let me see past all that. I thought, you just had a really, really bad life handed to you. She let me in. Then we found the happy medium of what she could tolerate and what she was requiring. Each day when I did her dressing was when we connected the most. We would turn on the stereo, put her favorite CD on, and we would either talk or sing. On the days when she was too sick or too tired, she would let me put on my favorite radio station and I would sing by myself."

Courtney was at her side when she died. "The day into the night that she died, it was very calm and peaceful, the opposite of her life. Several members of the nursing staff stood by her bed through her last moments, holding her hand, telling her who was there, that they were there for her — she deserved a little peace in her life. That was all she wanted."