In the Name of Good Intentions: Nurses’ Perspectives on Caring for a Pregnant Patient in a Persistent Vegetative State

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PRIME POINTS

- As direct care nurses, we encounter patients throughout our careers who leave an indelible imprint on our lives.
- With almost every encounter, nurses have the opportunity to learn something about themselves and redefine their values as they care for people in differing states of health and social circumstances.
- Individual perspectives are created when we view our patients through the lenses of age, moral and ethical values, and life experiences.

Think back to all of the patients you have cared for during your nursing career. Some of them really stand out in your memory, don’t they? There was the young man with terminal cancer who was the same age as your son, the father of 2 growing boys who lost his limbs to pneumococcal sepsis, the mentally retarded 65-year-old, so sweet, yet all alone as a ward of the court, and the young Marine who, years after his severe illness, still visits to bring the staff cupcakes on the anniversary of his hospital discharge. The diagnoses varied, the drips we titrated changed, and the specifics of care have faded from memory. What remains is the imprint made upon us from sharing our lives, however briefly, with these patients and their families. With almost every encounter, nurses have the opportunity to learn something about themselves and redefine their values as they care for people in differing states of health and social circumstances. The authors, coworkers in a medical intensive care unit, would like to share with the readers our personal encounter with one such memorable patient.

The following is a retrospective journal of the nurses who cared for Judy, a 22-year-old, pregnant, white woman with anoxic brain injury due to a heroin overdose. Rather than presenting a plan of care, the authors have chosen to document the thoughts, emotions, ethical struggles, and triumphs of her caregivers. The experience is presented from the differing perspectives of these critical care nurses, due to age, moral and ethical beliefs, and life experiences, as they cared for Judy, her...
growing baby, and her extended family. We hope that readers will journey with us and will find our experiences helpful when they encounter patients with similar or equally difficult situations.

**Admission**

The patient was brought to the emergency department after being found unresponsive by her boyfriend. It was not clear if she was ever pulseless or if this was primarily a respiratory arrest. Downtime unknown. Cardiopulmonary resuscitation had been performed by a bystander, and the patient was in sinus tachycardia when the medics arrived. The patient was pregnant with a fetus of 11 weeks' gestation. Medical history was significant for alcohol abuse, depression, and a previous suicide attempt. Computed tomography of the head showed no bleeding, shift, or mass. The patient exhibited decerebrate posturing and had an upward gaze. Fetal heart tones were present, and fetal movement was detected. While she was in the emergency department, an endotracheal tube was placed for airway protection and then the patient was transferred to the medical intensive care unit (MICU).

A multidisciplinary approach was used from the start. The emergency department physicians quickly brought on board specialists from medical intensive care and obstetrics/gynecology. Assistance for the family was offered by the chaplain's office and family support services. When Judy was admitted to the MICU, the team was expanded to include neurology, palliative care, and nurses from high-risk obstetrics. Representatives from this team attended multidisciplinary meetings approximately every 3 months throughout the patient's hospitalization.

Early in the hospital course, an ethics meeting was convened, with representatives from the involved departments meeting with the patient's parents and grandparents. The purpose of the ethics consultation was to lay the groundwork for future decisions regarding the patient and the fetus, and to determine whether mother or baby would be the priority. The severity of the patient's anoxic injury was clearly presented to the parents. Prognosis for meaningful neurologic recovery was poor, and the patient's ability to carry the fetus to term was questionable. At the end of the meeting, it was determined that the patient would receive aggressive care. Despite expressing a clear understanding of the prognostic picture, the parents were hoping for the miraculous recovery of their daughter and the safe delivery of her baby. The ethics committee supported this plan of care and agreed with continued treatment of the patient, the decision made more compelling by the pregnancy.

The ethics committee chairman continued to meet every few weeks with the parents throughout the patient's hospital course. As the weeks passed with the patient showing no signs of neurologic improvement, disagreement between the parents emerged. The patient's mother seemed to accept the stated prognosis for her daughter and became more invested in the safe delivery of the baby. The father, however, persisted in his belief that his daughter would make a full recovery. The staff provided the family with daily updates, which reflected the lack of improvement or change in mental status. Complications were treated as they arose with an emphasis on safeguarding the baby.

Brittney, 24 years old, ICU nurse for 4 years

I was in charge report when I first heard about Judy. I recall thinking, “Here we go, another drug overdose.” Then I heard one last sentence from the previous charge nurse, “By the way, she’s pregnant, but we’re not sure how far along.” The emerging clinical picture was one of severe

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anoxic injury with no indication of improvement since admission. It was probable that the patient would progress to a persistent vegetative state, and I anticipated that the family would withdraw care.

Jan, 60 years old, ICU nurse for 40 years

My first encounter with Judy’s family was as a member of the hospital ethics committee when we were called to discuss the case and offer guidance and support to this family in crisis. I felt that I could be unbiased and participate in the process without preconceived opinions. However, I have raised 2 daughters and am a grandmother, so my perspective was most closely aligned with that of her parents. During the course of the meeting, Judy was presented as an artistic and academically talented young woman, attractive and personable with a bright future ahead. I came away with the understanding that Judy’s parents fully grasped the severity of the anoxic injury and at the same time focused on the new life growing within her. Her parents, especially her father, stated clearly that Judy would not want to be kept alive if there was no chance for neurologic recovery. The obstetricians present suggested that the chances for a good fetal outcome were excellent, and the likelihood of the baby suffering from either the drug overdose or lack of oxygen was not significant. This information was openly questioned in the meeting by both staff and family, and it was clearly restated that the patient was expected to be able to sustain this pregnancy to near term and deliver a healthy baby.

Chris, 41 years old, mother of 2 teenagers, ICU nurse for 21 years

Judy could have been my daughter. In fact, they shared the same name. The realization that Judy wouldn’t recover was profoundly devastating. After the ethics meeting, the decision was made to incubate the fetus. My own internal conflict with this decision made it that much harder to support this family. What decision would I make if placed in this unfortunate circumstance? If this baby was successfully delivered, who would care for him/her? Legally the child could go to the biological father, not Judy’s divorced parents, but he was reportedly using heroin with Judy at the time of her overdose. Into what kind of legacy would this child be born?

Fran, 33 years old, ICU nurse for 3 years, previous career as a respiratory therapist

Even though I have been in the medical field for almost 10 years, it was emotionally draining to take care of Judy. I couldn’t understand how this beautiful girl could do this to herself and her growing baby. I have a friend who recently had a miscarriage and was having difficulty getting pregnant. Now my patient was a girl who seemed to have total disregard to what she was doing to herself and the life growing inside her. I was glad I wasn’t assigned to take care of Judy when she was first admitted because I knew it was going to be very difficult for me, emotionally and spiritually, given these circumstances. The fact that she had a severe anoxic brain injury and yet had a growing fetus that was supposed to be healthy was a paradox in itself.

Brittney

The longer Judy stayed with us, the more real the possibility became that she would carry this pregnancy to term. Her family brought in pictures and told us more and more about her. Judy was a beautiful girl, smart, intelligent, and artistic. Her parents related stories about her childhood and youth. The longer I was in the room and looked at the pictures and spoke with them, I realized she was not unlike many of my childhood friends. Judy had just chosen a different path. We cared for patients like this so often that...
we sometimes failed to connect and see them as the people they once were or could be. Judy was truly not that different from me.

Krista, 29 years old, ICU nurse for 3 years, previous career in marketing and management

It was sad to be alone with Judy in her room performing nursing care. Lots of pictures and cards surrounded the room and covered the windows. There were silk gerbera daisies and balloons. Judy’s favorite music could be heard on her CD player. Our staff got to know the family and learned of Judy’s dreams of becoming a teacher. We knew one of her proudest accomplishments was having her painting displayed at Ground Zero in New York City. Judy’s family was supportive. They called our staff “her angels.” I didn’t feel like an angel.

Judy’s paternal grandmother retired early to spend time with her granddaughter and sat by her side for hours every day. Her family remained hopeful, especially her father, who genuinely believed she would come home with him. When he noticed Judy making subtle movements, such as reflexive sucking noises with her lips, he felt she was responding to him.

Beckie, 48 years old, ICU nurse for 2 years, MA degree in psychology, former therapist

Judy’s mother called each morning to ask if her condition had changed, sometimes remarking that the grandmother told her she seemed more responsive. I reported to Judy making subtle movements, such as reflexive sucking noises with her lips, he felt she was responding to him.
antibiotics and, although they were deemed “safe” for the fetus, I still had my doubts that these medications would not adversely affect fetal development. In addition, I wondered what effect Judy’s heroin use and the initial anoxic injury would have on the fetus. My hope for her family, as well as everyone involved in her care, was that the baby was healthy.

**Jan**

As time progressed, I saw that the parents still had hope for the neurologic recovery of their daughter. It became more and more clear that no amount of explanation or reinforcement of Judy’s brain injury would change this viewpoint. For me, the most difficult aspect of caring for Judy was presenting the truth in a way that was not cruel but that left no room for false hope. My goal throughout all of this was to make certain the parents were well informed and capable of making good decisions on behalf of their daughter.

**Fran**

As Christmas approached, Judy’s mom decorated her room with a white Christmas tree and purple ornaments. I played the Christmas music that her family brought in for her. Wouldn’t it be a wonderful Christmas present if Judy did wake up and the baby was healthy? I sometimes found myself too optimistic. I knew medically Judy was not going to recover, but I wished we were wrong. Judy’s father would come in and visit and tell me that they were getting ready for the baby since he and his wife planned to adopt her. Then her mom would come in and see Judy’s condition and get very upset. As much as I wanted to tell them that everything was going to be okay, I couldn’t. All I could do was listen. I didn’t really know what to say. Instead, I focused on making sure Judy received good care. Doing little things like braiding Judy’s hair helped me feel like I was doing something for her and her family.

**Beckie**

The family brought in a miniature Christmas tree and decorated it in Judy’s favorite colors, and a homemade CD of Christmas carols plays in the background. Judy loved Christmas. I wanted to scream, “Don’t you people get it? Judy is not coming back.” This “happy young woman” felt enough pain and emptiness to snort poison as a means of finding comfort . . . enough alienation to turn to a substance instead of people to seek relief. But then it occurred to me that the wall of denial I met when I tried to tell this family the reality of Judy’s condition paralleled the wall of denial they used every day to cope with her drug abuse. And Judy’s behaviors then were no doubt as misinterpreted by her family as her reflexes were now. Denial. This family was good at it. They had organized themselves around it. Judy used it to hide her self-destructive behaviors from her family . . . walked among them while remaining inaccessible. The focus of their denial had changed, but the functioning was the same. Again this year, Judy had brought her family together for the holidays. And again, she remained present but unreachable.

**Treatment Notes, Month 5**

Shortly after the holidays, the patient was transferred to the surgical critical care complex at the request of the attending obstetrician. This move was made to locate the patient nearer the delivery suite and neonatal nursery. Care of the patient was transferred from the MICU team to the team in the surgical critical care complex.

**Delivery**

At 32 weeks’ gestation, the patient was delivered of a 6 lb, 4 oz (2.8 kg) female infant by caesarian section. The initial Apgar score was 5 but climbed to 8 within minutes of delivery. The baby appeared to be healthy. The parents had previously consulted with a lawyer and been told that custody could not be awarded before the birth. A family decision was made to have the patient’s father take custody of the baby in spite of his current wife’s chronic health issues. At delivery, however, for reasons not shared with the medical team, the baby went home with the patient’s mother—the first of many indicators that communication among the principals was starting to break down and that future decisions concerning care of the patient and her child would not be reached amicably.

**Fran**

When the baby was born, we were excited that she seemed to be healthy, and a group of us bought her a present. Judy’s mom was very appreciative. At the end of Judy’s stay in the hospital, there was more disagreement between her parents regarding who would assume care of her and the baby. Her father was still in denial about Judy’s recovery and could not focus his attention on his new granddaughter. I had hoped...
that this child's birth would remind them of the joys that a new baby brings. How unfortunate that so much turmoil remained.

Chris
Several months had passed since the birth of the baby. Judy was now living in an assisted care facility, and her neurological status was unchanged from the time of hospital discharge. I stepped onto the elevator to go to lunch, and Judy's father was standing in front of me. Judy was back in the hospital with severe pneumonia. I asked about the baby and he stated he had not seen her since she was born because Judy's mother would not allow it. A court date was scheduled in a few months. He said a neurologist was following the baby's growth and development.

Jan
After delivery, when communication had completely broken down between the patient’s parents, I was haunted by unanswered questions. Why were the medical professionals unable to present a clear enough picture to all parties that would have allowed them to reach a consensus about the best plan of care? What legacy would be passed to this infant girl and what would she be told about her mother, especially if Judy remained alive but unaware of her daughter’s existence?

Krista
I struggled most with not having closure with this situation. We had invested so much time and effort into her care but were not able to see the outcome. At the same time, I didn’t know if I wanted to. Judy’s family proudly showed us pictures after the birth of her newborn. I heard from several sources, including her family and health care providers, that the baby was “healthy.” I remained pessimistic that our medical interventions would have an effect on the developmental outcome of the baby. I could only pray that the baby continued to be physically healthy. More importantly, I thought about her psychological health as she entered this world surrounded with conflict and wondered if ultimately we had done the right thing. Unfortunately, Judy didn’t realize the potential she held as she struggled with addiction. Now her future would be played out with end-of-life decisions made for her by her parents as they faced custody battles over her newborn daughter.

Discharge
The patient was discharged from the hospital 1 month after delivery. She was admitted to a long-term care facility under the care of hospice, with a new do-not-resuscitate order in place. She was maintained on a tracheostomy collar and enteral feedings, with no measurable change in her neurological status. When this article was submitted for publication, the patient had already had multiple readmissions to the hospital for treatment of infection. Her father dismissed hospice and rescinded the do-not-resuscitate status. There is much discord between her parents about whether or not she remains in a persistent vegetative state. A consensus cannot be reached concerning an advance directive or whether tube feedings should be continued. A court battle is in progress to determine guardianship of Judy and custody of her daughter, with the baby’s father seeking an active role.

Conclusion
In a way, Judy presented a composite of many of the cases we see in the MICU, replete with the tragedy of self-destructive choices and the ramifications of those choices on others. We meet “close” families who know little of each other and are overwhelmed by regrets, and others who wrestle with unrealistic expectations that become issues of futile care. As with most of our cases, many disciplines were involved in Judy’s treatment and put much thought and heart into decisions about her care. Yet, as is always the case, the true constant throughout Judy’s tenure with us was the presence of the critical care nurse at the bedside. It was the nurse who continuously addressed Judy’s most crucial and intimate needs while she was at her most vulnerable. It was the nurse who comforted the family members, understood their loss and pain, and tried to gently dissuade them of their denial. And it was the nurse who often stood alone in the room with Judy, surrounded by pictures of her too-short life, listening to her music, seeing her limbs contract and posture with any stimulation, and watching as her body changed with the growth of her unborn child.

It would seem that critical care nurses, while differing in life circumstances, are still cut from a common cloth: appearing to thrive on the adrenaline that comes with life-and-death situations, able to maintain calm efficiency in the midst of great tragedy and sorrow, willing to share strength and comfort with...
family members who are still in shock, and ready to move on to the next patient minutes later because there will always be another room that has just been posted.

All nurses know that patient care is a 24-hour job requiring the participation of many hands. So we laugh whenever we can, support one another in whatever way we can, and try to leave the job at the hospital whenever we can. We somehow learn to take the “Judys” we encounter every day in stride and move on. Some of us are more successful at this than others. The factors that made Judy more difficult than our average patient were the length of time she was in our care, her age, the special circumstances of her past, present, and future, and the intensity with which we worked with her and her family. Instead of a fleeting glimpse of a patient’s life, we each saw Judy up close, magnified through our own personal lenses. Some saw a daughter, some a sibling, some a mother who would never hold her baby. Some saw ourselves, all with the knowledge that “There but for the grace of God…”

Many of us were working right before Christmas this year when Judy’s mother brought Judy’s 10-month-old baby to visit, and we had our pictures taken with a beautiful baby girl who has her mother’s eyes and hair. We listened as Judy’s mother talked about the baby, shared her concerns about what she will tell the little girl of her mother as she grows up, and understood her pain as she spoke of Judy’s continued physical deterioration and the legal wrangling for custodial rights. To date, Judy’s father has never seen his granddaughter in spite of multiple offers to visit by Judy’s mother. Although the issues and our feelings remain complex and conflicted, perhaps we are now more willing to discuss them freely.

In writing this article, we have finally come together to talk about the case and process our feelings and experiences about Judy’s treatment. There is a strong temptation to wrap this in a nice, neat package, replete with universal insights predicated on lessons learned and evidence-based clinical applications for use in future cases. Herein lies the problem. The aspect of this case on which we chose to focus is the human story, the intricate narrative that each patient and each family member brings to the hospital. It is composed of raw, complex emotions and reactions, people and relationships with all their strengths, histories, and frailties. Sometimes we find ourselves wishing these elements of our work actually could be wrapped neatly into packages for presentation, but this simply has not been our experience.

In approaching this article, we chose to review Judy’s “story” primarily as participants rather than observers of the medical process. Being able to sit down together and share our experiences around Judy’s story was possibly the greatest benefit of this endeavor, as it afforded us an opportunity to learn more about ourselves, each other, and the work we choose to do. Most certainly, it should have taken place much earlier even without the article as a catalyst. Perhaps this is the essence of what Judy taught us and what we will each take with us as we prepare for the next patient.

To learn more about the neurological aspects of critical care, read “Development of the American Association of Critical-Care Nurses’ Sedation Assessment Scale for Critically Ill Patients,” by De Jong et al in the American Journal of Critical Care, 2005;14:531-544. Available at www.ajcconline.org.

Recommended Reading


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None reported.
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