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Ronald Wyatt MD
rwyatt@mcic.com

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His story: “I would be better off dead”

Ronald Wyatt, MD, MHA, *VP and Patient Safety Officer MCIC Vermont, rwyatt@mcic.com*

Abstract

A physician shares the story of his brother’s experience in an ICU, how the hospital caring for him failed him as a human being, and how the pain of not being properly cared for and not being treated with dignity and respect left the patient feeling he would be better off dead. In the back of his mind the patient wondered if it was because he is Black. The story prompts the author to reflect on patient rights as a reminder that healthcare is called to serve, to love, to be empathetic, to be respectful, to be humble, to listen, and to be trustworthy. Re-establishing trust with the people and communities that healthcare serves is the hill that all in healthcare must climb together to ensure his brother’s story is never repeated.

Keywords

Joint Commission Patient Rights Standard, discrimination, patient experience

My brother has advanced stage myeloma. After diagnosis, he was started on multiple immunosuppressant medications and external radiation to his skull, ribs and cervical spine while awaiting a stem cell transplant. After a few days with a rash and fever, his wife took him to the emergency department of a large, accredited healthcare system. He was admitted to the ICU with acute renal failure and septic shock and was given IV fluids, three intravenous antibiotics and IV medications to elevate his blood pressure.

His wife has been recovering from a cerebral hemorrhage that left her with mild motor weakness. This occurred at the peak of COVID-19 in 2020. After his admission, he was told that he would need hemodialysis which terrified him and his wife. She was not allowed to visit him due to pandemic restrictions.

My brother is a senior supervisor with a federal agency and holds a master’s degree in computer engineering. My sister-in-law was a coding specialist for a hospice but now unable to work. She called me and shared that her questions were not being answered by the care team or nutrition and social services.

With his approval, I initiated a phone call with his ICU team. The ICU hospitalist began the conversation by saying, “Well you know when these people come in...” at which point I interrupted him and requested that he begin again, because my brother has a name.

He told me that my brother was in acute kidney failure and has a rash from an adverse drug reaction. The physician then said that my brother’s kidney function had improved but after I asked for objective data, it was clear that there

had been a worsening of his kidney function and when challenged the physician had no response. One day later, my sister-in-law called in a panic because my brother had been transferred to a medical unit.

The very next day he was discharged, and his wife was told to come pick him up. When she saw him, she said that he was “filthy.” He had not met with a care coordinator and had not been offered a bath or shower. He began to cry and said that by the way he was treated, he would be better off dead.

Once he was home, my brother and I talked. He said to me that he was treated like a checklist. The care, he said, was technically acceptable but “they did not see me.” He went on to say that he wondered if he had been treated that way because he is Black.

After hearing this, I called and asked to speak with the chief medical officer. A few days later, the system chief medical officer called me and immediately said after a comprehensive review of my brother’s care, he had concluded that “we failed him.”

According to the Joint Commission Patient Rights Standard, you have rights and a role regarding your treatment and care including:

- You have the right to be informed about the care you will receive.
- You have the right to get important information about your care in your preferred language.
- You have the right to get information in a manner that meets your needs, if you have vision, speech, hearing or mental impairments.

- You have the right to make decisions about your care.
- You have the right to refuse care.
- You have the right to know the names of the caregivers who treat you.
- You have the right to safe care.
- You have a right to have your pain addressed.
- You have the right to care that is free from discrimination. (This means you should not be treated differently because of:
 - Age
 - Race
 - Ethnicity
 - Religion
 - Culture
 - Language
 - Physical or mental disability
 - Socioeconomic status
 - Sexual orientation
 - Gender identity or expression)
- You have the right to know when something goes wrong with your care.
- You have the right to get a list of all your current medicines.
- You have the right to be listened to.
- You have the right to be treated with courtesy and respect.
- You have the right to have a personal representative, also called an advocate, with you during your care.
- Your advocate is a family member or friend of your choice.

After reviewing these standards with the system CMO for hospital medicine, he replied, "I need to listen to you, because it is clear that we have a lot to learn." Then he asked me if I thought it was okay for him to call my brother.

A few weeks later, my brother went for a dental visit. His dentist, an Asian female, told him that she had been cared for by the same system during her pregnancy and that she had almost died from a post-partum hemorrhage. She, too, felt she had not been listened to. She went on to share that the Asian community in the area knew not to seek care at the same system that had failed my brother. She advised him to never go back.

Now that value-based care is a reality, one of the areas of focus is person and community engagement, defined by the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey dimensions of:

- Communication with Nurses
- Communication with Doctors
- Responsiveness of Hospital Staff
- Communication about Medicines

- Cleanliness and Quietness of Hospital Environment
- Discharge Information
- Care Transition
- Overall Rating of Hospital

The HCAHPS measures frame a significant commitment for care and higher scores should indicate higher quality. They also provide a lens through which to assess our own care. In reflecting on my brother's experience and looking at these dimensions, it was clear that not only did my brother's treatment not meet his expectations, but it also simply missed the mark for a quality experience overall.

This resulted in his internalization of the experience to the point that he felt that he would be better off dead. He felt devalued, de-humanized, disrespected, his dignity was taken, His wife and advocate was not cared for, which left her anxious, depressed and isolated.

We are climbing a hill. This hill must be climbed together. The poet laureate, Amanda Gorman, challenged all of us with her words at the Presidential Inauguration and I will paraphrase from her poem, "The Hill We Climb":

"When day comes we ask ourselves,
'where can we find light in this never-ending shade,'
the loss we carry,
a sea we must wade?
We've braved the belly of the beast.
We've learned that quiet isn't always peace,
and the norms and notions
of what just is
isn't always just-ice.
And yet the dawn is ours
before we knew it,
somehow we do it."

Somehow, we've weathered and witnessed that our healthcare system isn't broken but simply unfinished.

We are called to serve. We are called to love. We are called to be empathetic. We are called to be respectful. We are called to be humble. We are called to listen. We are called to be trustworthy.

Begin with apologies where needed. Work to correct historical insults. People and communities must trust us again. It is urgent that we do not just the hard work, but the heart work. We cannot be big and small at the same time.

Let's not repeat his-story. Let's commit to going big.