POINTS OF VIEW

What Is Liberty? Addressing Undeserved Suffering in Health Care

"What brings your loved one here?" the hospice nurse asked. She was seeking an abbreviated history of my mémère's terminal diagnosis, but I couldn't muster the words without losing my composure. Somehow, the nurse understood. She said, "Tell me about Mrs. Rosalie."

"She doesn't want to suffer. She suffered all her life," I began.

My mother squeezed my shoulder and nodded.

"No restraints," I added. "She doesn't like them."

She'd been restrained enough. Abandoned as a child, she was repeatedly tied to a bed in an asylum for insane colored children, until the warden took her home to assist his wife with chores. Afraid she'd be institutionalized indefinitely, she ran away. Left unvaccinated, she contracted diphtheria at age 12. She married a man 6 years her senior who'd also been abandoned. At 15, she gave birth to the first of seven children. To get her family public housing, she had to oust her husband. She was assaulted in the stairwell by a neighbor. She worked two jobs to escape a notorious housing project. She finally became a homeowner, but at what cost?

The nurse listened, setting aside the prescribed intake process. I was grateful that in this final hour, she wanted to examine the details of my mémère's health, to unpack her pain.

Was this moment the liberating, comprehensive health care experience my grandmother had long awaited? During the Covid-19 pandemic, as many Americans have been awakened to implicit biases in health care, the ramifications of social injustice for the value of Black lives, and the shared disparities in outcome whether one is shackled to an underresourced safety-net hospital or a dehumanizing justice system, I've been reminded of Gustavo Gutierrez's liberation theology and the public health applications of its approaches to achieving social justice. Embracing a preferential health care option for society's most vulnerable would acknowledge that health care is a human right demanding equity and justice. But there is no liberation in health care for the poor, just symptom containment.

The health care system saw Mémère as a collection of patient identifiers — medical record number, date of birth, last-name-first-initial. They butchered the spelling and pronunciation of her Louisiana French-Creole surname. They accused her of poor understanding when she didn't respond. Ironically, she accused them of the same. Overworked and overburdened, they were dismissive of her person, reducing her to a list of conditions — hypertension, high cholesterol, prediabetes.

In that moment of reflection, I recalled the chants in homage to Sandra Bland, "Say her name. Say her name."

"She likes being called Rosie," I said. The nurse smiled politely.

The years had taken their toll. Mémère was poor, Black, undereducated, and now unkempt. She had been encouraged to quit smoking but offered no treatment options. Smoking-cessation drugs were not covered by her health plan. "My nerves are bad," she would say; "I can't just quit."

So she puffed her problems away. Clinical depression; the loss of two sons to gun violence; the loss of grandkids to the penal system; the loss of her partially paralyzed husband to "John Henryism" (the psychosocially influenced workaholic coping strategy that results in poor health in Black men); the loss of sleep from guarding the door.

She would wait for me at the bus stop after school. My private school uniform made me a target on public transportation, and one day I was robbed. I emerged from the bus crying, but she didn't care that my money was stolen — she rushed over to check whether my body had been violated.

For years, the health care system swiped her

copays and neglected her being. She thought she was unscathed, but she had been violated — picked clean for profits rather than protected.

In reality, she was not prediabetic: she drank coffee before the fasting glucose test. She didn't have uncontrolled hypertension: afraid of soiling herself on public transportation, she didn't take her diuretic before appointments. She worked until her body failed at age 82. After 6 months of weight loss and 4 months of delayed tests, she was diagnosed with metastatic lung cancer in the emergency department. It took terminal cancer to get social work and case management involved. For years, health care had contributed to, rather than healed, her suffering. Yet she never missed an appointment.

Tragically, protests and policy measures won't be effective until there is first a change in praxis. For America to be truly free, there must be liberation for our most vulnerable and recognition of their humanity — even in medicine.

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