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Starting the Conversation

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“You don’t seem to realize the fact that you’re white.”

The voice on the line stung with derision, palpably piercing my senses more directly than the westward summer sun blanketing the balcony where I sat. I was home, near Chicago’s Loop, and that call to a colleague on the south side of town unsettled my surroundings that just moments ago were comfortable. I twitched with new uneasiness in my skin, fair but reddened by the season’s recreation.

“Is that really what you want me to know?” I asked timidly, the confident tone once transparent through the telephone had transformed- crumbled, perhaps- to credulity.

“Yes, because they’re not going to like that message, especially coming from you,” she replied, unaware of the capacity her words had to wound.

I had not given much consideration to race when embarking on the project at our conversation’s core, but my own race wasn’t something I took for granted. I looked out from a more privileged perspective upon a city cut into colored chunks, along racial lines. In my work as a journalist- a street reporter- I had spent a decade knocking on doors, sitting in schools and attending meetings on Chicago’s streets-straight lines of color- black, brown or white. Though residents may not have mixed with each other, they mixed with me-eager to share what mattered. I was equally eager, ready to record and replay it on the evening news. The difference between their race and mine didn’t keep them from wanting to be heard, and I thought this instinctively human desire could drive the project to success: promoting self-determination among Chicago’s senior citizens when they neared the end of life.

That’s the reason I called her: an African-American minister familiar with healthcare challenges within her congregation. She was dedicated to palliative chaplaincy and reinforced stereotypes my friends in medicine sometimes lamented.

“My people,” she called them, “will always do *everything*.”

Not knowing what to say, I said nothing. Perhaps I feared saying the wrong thing, knowing this conversation had taken a turn I didn’t know how to navigate tactfully. I could widen a divide already deep.

While reasons behind the minister’s rationale were valid, I knew statistics and stories didn’t support her claim. Most don’t want *everything*; what most want when they die is to be comfortable, pain-free and surrounded by those they love.

“I’m sorry to hear that,” I responded, finally getting out words.

Her generalizations were not always the case, and when they were- I surmised a dearth of information sometimes drove them. Stereotypes ticked me off, while the notion they were “her people” put me off. It also got me off the phone.

They were not her people, any more than those downtown were mine. Neither were the Puerto Ricans a mile west those of my late husband; his death from colon cancer at 36 a few years prior drove my decision to enter end-of-life care education.

The minister’s sentiments were difficult to shake as I opened the squeaky metal doors of the municipal building a week after that conversation. Mary and I were there to have a conversation ourselves, one we hoped would go better.

Mary is white, too, with a freckled, ruddy Irish face. However, as a medical oncologist, she had faced many patients who had given little thought to their end-of-life care. She knew the main reason why: most providers, like herself, gave little thought to giving patients the time and place for such considerations-when they were healthier and thinking more clearly than when she met them, on or close to the worst day of their lives. The day of diagnosis.

Because these conversations weren’t happening in her office, or those of her peers, she was heading out with me to have them where they could perhaps be better facilitated- on neutral, neighborhood ground. Without lab coats, stethoscopes and sterile scenery of exam rooms. Without facing emergent crises.

Mary and I first collaborated months prior, believing our skills as physician and journalist could communicate clear messages of empowerment regarding end-of-life issues. From our vantage points as provider and caregiver, we saw realities representing data: care was not aligning with patient preferences. Americans across the country and neighbors in Chicago were not dying in the ways they wished. The issue is unique within healthcare because it is the opposite among patients. The universality of end-of-life experiences drove our urgency to encourage all to speak up and spell out the healthcare they want.

Beyond that squeaky door, a receptionist smiled beneath the sign: *Englewood Senior Center*.

“You’re the ladies in the photo,” she said, standing up, leading us to our podium.

“What photo?” we asked simultaneously.

“The photo on the flyer,” she exclaimed, pointing to the bulletin board-surprised we didn’t know how this worked.

Our nervous laughter lent evidence this visit was the first on our tour of 22 senior centers. The Department on Aging invited us to visit 60 and older patrons in every neighborhood, talking about end-of-life discussions, how to start them, and how to document preferences in advance directives.

We called our presentation, “Starting the Conversation,” and the warmth of the receptionist in an Englewood community I had only previously visited for crime-centric news coverage will be remembered. The institutional walls and linoleum floors seemed coated with kindness entirely unexpected.

I dismissed the minister’s forewarnings and my recollections of trips to this block. Inside the community room were two-dozen seniors on a Tuesday morning, seeking refuge from loneliness in the company of peers. But they also waited to hear from two traveling from 60 blocks away. Two much-younger ladies-ones they knew from the flyer happened to be white.

I was anxious, but the turnout was a positive sign. We were there to help, and unlike prior visits to this area-I wasn’t looking for anything to take back up the Dan Ryan expressway to a downtown news studio. This trip would be for the seniors’ benefit. We were giving time, hoping only for attention in return.

Perhaps our talk wasn’t taboo. Perhaps we were accepted.

One hand was raised.

Nodding to a warm-up suited-woman, I said “hi.”

“My kids won’t discuss it,” she projected mindfully, ensuring friends older and frailer could hear. “I don’t know what to do with them, but I know what they’ll do with me!”

“What’s that?” Mary smiled.

“Keep me around forever! But one day, I’ll be ready to go!”

We were off-script, but it didn’t matter. Three others nodded-hers was the reason they were here.

One voice followed another, and then one more. They were ready to talk. Some stories centered on health challenges of friends-intubated in intensive care units where they never wished to be. Others discussed their own health scares and fears harbored about sharing care wishes.

Some questions we could answer:

“How do I talk to my daughter?”

“Why hasn’t my doctor addressed this?”

“Will I be uncomfortable if I opt against artificial nutrition?”

“How do I choose a decision-maker?”

“What do I do with my advance directive?”

Others were harder:

“What if I have no family to speak for me?”

“What if I trust no one with my care?”

It wasn’t hard to fill our one-hour slot, before the 11 a.m. Zumba bell chimed. This crowd was active and healthy (two impressive indicators I noted) assuring them this was an ideal time to talk. Tough decisions aren’t best made in times of stress or crisis.

Mary outlined options for consideration. This was the first time most had heard implications of intensive and non-intensive care. Most medical talk was new to them; many technological measures were not ones their grandparents had the option of choosing.

The seniors then heard from me. We had a conversation about conversation itself and how to discuss tough topics. Reluctant adult children, I said, can often be persuaded to

listen when conversations are framed differently. The seniors knew they were doing loved ones a favor in expressing preferences, but many loved ones wouldn't hear it.

Instead, I explained, ask them to do a favor for you. Ask them to give you the gift of time. Deep down, the seniors knew this gift is theirs to give. Deep down, I hoped to give the seniors gifts of clarity and confidence deserved after lifetimes well-lived.

Everyone left for Zumba with an advance directive. If they did nothing else, we asked them to appoint a surrogate decision-maker. Most asked for extras for family members and neighbors. A few called that night to ensure they completed the form correctly.

With one center visited, Mary and I had 21 to go. The seniors may have looked different, but the concerns were the same.

"No one wants to talk about this!"

"How do I have the final word?"

"How do I make sure my daughter doesn't pry me from bed and to the E.R. when I'm taking my last breath?"

Though thoughts were shared through smiles, concerns were serious. We took surveys at each stop and the responses reflected reason for worry. The majority of the seniors had never discussed end of life care with anyone, even though a similar majority said they thought about care they desired. Most knew who would speak for them in a crisis, but most had never discussed this with that person. Most had never heard of advance directives. One in ten had completed an advance directive, fewer than the national average.

The disconnect between the end-of-life care most receive and the end of life care they desire led us to another disconnect in our city- a knowledge gap. Seniors weren't preparing for end of life care. Not because they didn't want to plan. Not because they didn't want to discuss it. Not because they wanted *everything*. They weren't planning because no one had taken time to show them how and answer questions bothering them. Questions they had, until then, were kept to themselves.

Many health care providers say the biggest challenge when patients don't outline preferences is trying to guess for them, often picking between bad options. The patient, intubated or unconscious, has no say.

Voices in Bioethics

One senior center at a time, Mary and I are trying to give more seniors a say. We're going back this fall, and with each visit, we hope we get better in helping the voiceless find a voice. No matter what divides us, those differences dissolve when discussing the basic desire to be heard. It seems like a fundamental right: When it comes to our own healthcare, we all should have the last word.

I'm glad I didn't allow the minister's last words to determine our project's fate.

This city's seniors? They are *our people*. Listen to what they have to say.