

## Another Look at Dying

By Flo Gelo

They were lonely women. They had almost nothing. One was an onlooker. One found a prize. As a chaplain, I watched their friendship unfold.

I remember the blustery February afternoon when Lorraine, a newly discharged hospital patient, arrived with her bright purple and orange nylon travel bag and became Regina's roommate. Regina had been admitted a few months earlier after living in a skilled nursing care residence.

She was recovering from a stroke and, upon discharge, had no home or family to go to. She required ongoing care to address problems with balance and walking. Regina had arrived with her belongings in a dark cranberry tote bag, her name printed below a faded image of the Philadelphia skyline.

When Lorraine unpacked, she took from her travel bag several framed photographs. A small surface on the bedside cabinet was too small for her to see each picture and the favorite memory it captured. Regina offered to have her cabinet moved between the two beds so Lorraine could show the remaining photographs. They would share the cabinet. Regina would keep the drawer for her clothing and the Gideon bible that she found already there.

In the early weeks of their budding friendship, Regina and Lorraine happily discovered the pleasures they shared: tapioca pudding, baseball, and big band music. The one crucial and ongoing debate between them: "who was the best," Duke Ellington, or Count Basie? This passionate and constant debate was a sensation among nursing staff who google searched, took sides, and asked me to certify their decision, the Count or Sir Duke?

Neither Regina nor Lorraine could walk. Lorraine was bedridden and, for periods of time, Regina was able to sit in her wheelchair. She would ask an aide to wheel her towards Lorraine's bedside, and there they contentedly looked through Lorraine's forty-year-old wedding album. One day I arrived when Lorraine and Regina were huddled together, staring at the page of photos, lingering over one and grinning. Lorraine enjoyed sharing the memories of her wedding day, her five bridesmaids, her husband Emmett's tuxedo and bow tie, the feast of oven-roasted chicken with gravy, ham roast, collard greens, green beans, stewed cabbage, candied sweet potatoes, and macaroni and cheese. Lorraine took special pride in her 3-tiered wedding cake but no less in describing the table of desserts like fruit cobbler, chocolate, fruit pies, and a five-layered red velvet cake that her mother-in-law baked for the ceremonial day.

Sitting up in bed with a flattened pillow supporting her back, Lorraine spilled out stories one after another. Lorraine reminisced about the years she and Emmett shared - years full of activity and love, of church, family, and friends who took the time to care and genuinely love each other. These buffered the cruel realities of life I know they must have experienced beyond the home: Emmett's low-paying job as a bookkeeper for a small business; everyday insults toward dark-skinned people that never diminished his pride. Lorraine praised his ability not to reply when a coworker complimented him on how well he dressed for work or "Oh, you like to watch Bogie's films." The challenge and heartbreak were the couple's stress with Emmett's ongoing medical and care needs from heart disease, depression, and then his sudden death from a heart attack in his mid-fifties. Regina and I listened carefully as Lorraine recalled the many joys and disappointments in her life. Regina responded to her every word with a facial expression, from shock, to smirk, to grin, to furrowed forehead.

Lorraine and Regina found comfort with each other. I believe the conversations eased their loneliness and offered Lorraine a chance to struggle with her fears. Both Regina and Lorraine were "total care" and needed oxygen which was their lifeline. Lorraine, however, was afraid of oxygen, imagining that someone might accidentally or intentionally take it away, that a power

failure would occur, or that a fire might ignite while she slept. She often confided to Regina an obsessive thought fueled by distrust of the medical world, "There's money in it, you know."

As their chaplain, I often arrived along with the noon meal. That daily ritual, the food that arrived on the grey plastic tray that fed their bodies, was simultaneously nourishment that awaited me as we engaged in small talk and companionship. Both women valued my presence as I became a predictable visitor and, often, the referee for their debates. At times, I served as witness to their suffering and to their joys.

Lorraine began having difficulty eating. She complained that her plate was too full. She left chicken and broccoli spears untouched. Some days she never unfolded her napkin and let food drop to the floor. Yet she requested daily strawberry Jell-O with fruit cocktail, enjoying its slippery cool texture.

One afternoon Regina greeted me with a notepad. Scribbled on the pad was, "She's more unhappy today." Lorraine lay in bed, eyes closed, lips quivering. Regina told Lorraine, "The chaplain is here." Lorraine responded with eyes squeezed closed, "I know." Regina showed me the word puzzles given by the social worker to Lorraine each day. This day, Lorraine was too distracted to share the activity with Regina. "It's remarkable," Regina whispered, "her friends have become my friends. The people who take care of her, they visit me." "You take such good care of her," I said. "Me? she's my friend," Regina said, punctuating the word "friend."

Lorraine dislodged the oxygen nose piece as Regina and I spoke and placed it by her wet lips. She put it back and said, "I have to check this often to be sure the oxygen is coming out." Again, Regina whispered to me. "This thing upsets her most. She doesn't think the nurses come in enough to check her oxygen. Her nose hurts. Sometimes it bleeds and she is afraid of suffocating if her nose swells up and she can't get enough oxygen. Also, they should check her

bedpan every hour, but they don't and it's upsetting to her that the filled pan stays on her bed after she has used it.”

Hand clenching the armrest of her wheelchair, Regina continued, "She doesn't get her Motrin on time. I don't either. Lorraine is total care. I'm almost total care. Nurses don't understand that they are all we have to take care of us. "

Time passed as Regina devoted herself to the increased demands to provide Lorraine with daily support. This care was made more challenging as they shared awareness of Lorraine's declining health. Regina would wrestle to put Lorraine's arms through the sleeves of her blouse. Once on, she would not button her blouse. Lorraine's increasing fear about breathing and growing impatience with the perceived slow pace of staff tending to her needs made her angry and uncooperative.

Regina and Lorraine's shared conversations and activities, watching Good Morning America and Dish Nation were no longer fun, not since they anxiously debated whether Porsha Williams, actress of Dish Nation, left the show on maternity leave. Regina's grief now dulled the mutual pleasure as Lorraine grew weaker and more fearful.

Suddenly Regina lost the emotional energy to manage the speed with which Lorraine declined. Lorraine could no longer feed herself, and the wax cotton Batik blouse that moved, almost daily, from her body to the laundry and back was no longer. Instead, she stayed in a hospital gown for the entire day, every day. Regina still protected Lorraine by praising her, even for sitting up in bed for five minutes and shrugging her shoulders.

Lorraine entered hospice care and was moved to a private room to permit family and friends to visit for longer periods of time and to allow for religious rituals and ongoing spiritual care as

requested. In this room, filled with light streaming in from large windows, a Mason jar filled with daffodils sat on the windowsill. Lorraine was actively dying.

Meanwhile, Regina kept talking about her absent friend and roommate. Regina's recall of her many conversations with Lorraine, shared with the chaplain after Lorraine was moved to hospice, revealed the pain that Regina felt as she lost her friend and roommate. "We talked a lot about everything we were going through; now I got no one."

Regina also talked about her own unfulfilled yearnings. She mourned for a loving marriage that she never found. She remembered the heartbreak after the deaths of her best friend, her sister, and mother. One by one, she lost those who were important to her, those who she loved. Now she was losing Lorraine.

Days after being separated from her friend, Regina refused to leave her room. She complained that she was too exhausted to join others in the common dining area. She protested the staff's efforts to provide for her daily care needs. She would not let anyone comb her hair, clip her nails, or brush her teeth. Toothcare was off-limits! She had a new roommate but refused to talk to the woman; instead, she kept her curtain drawn and sulked.

At first, staff was impatient with Regina, perceiving her as being difficult and uncooperative. What was challenging to realize, maybe because nurses weren't accustomed to witnessing such a rare friendship, was that Regina had been stripped of her role as protector. Regina's behaviors were classic signs of someone struggling with an agonizing loss of love formed by the shared circumstances of long-term care. Regina was grieving.

During one visit, I helped Regina out of bed and sat her comfortably in a chair, and secured the curtain for privacy. She was angry that she had a new roommate, one that was "nice enough ...but I don't want to talk to no one."

Regina told me during our visit that she was “mad” at herself for not being able to stop Lorraine from suffering then dying. “I was her friend. She trusted me.” In my decades-long ministry as a hospice and hospital chaplain, I had never witnessed such a deep and urgent love develop between two residents.

Noticing the flood of visitors that were now visiting Lorraine and having spoken to the head nurse, I knew that Lorraine was actively dying. I asked Regina if we could visit Lorraine together. Regina refused, saying "I don't want to see her like that," and asked, "Is that ok?" We talked, and I was left thinking that the combination of Regina's own declining health, fears of the unknown future, and her expressed wish to protect her memories of the "happy days" with Lorraine was difficult to manage. Regina could no longer trust her feelings. I assured Regina that it was okay to let go.

When I helped Regina lay back in bed, I saw a picture frame tucked beneath her pillow. I guessed that Regina must have kept a photograph of her dear friend Lorraine when Lorraine and the staff transferred her belongings to the other room.

I was impressed with Regina's tenacity. I imagined Regina going to sleep each night and waking up each morning to a beautiful image and the feeling of tenderness for the one she loved.

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Flo Gelo is a medical humanities educator with over twenty-five years of experience working with patients receiving palliative care. She has published numerous articles in professional journals about illness, death and dying. Gelo, who uses the visual arts as a teaching tool to enhance clinical skills in medical education, most recently employed used images of narrative paintings to assist hospice patients to speak about the day-to-day realities of living while dying. She has also produced "The HeART of Empathy: Using the Visual Arts in Medical Education" selected by the Family Medicine Education Consortium (FMEC) as their 2009 Family Medicine Through the Visual Arts Award, as well as Emma's Haircut, the story of a 32-year-old mother of two, having a shaving party when she undergoes chemotherapy for breast cancer.