

CHAPTER 13



Breaking Bad News to Low-Literacy Patients

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While growing up, Carla loved her Hispanic ethnicity. Determined to live happy and free in the city, she envisioned herself surrounded by family and friends, dancing at quinceañera celebrations and local salsa clubs. She never spent much time worrying about perfecting her English or her future, and she dropped out of high school in the 11th grade.

When Carla was 17, her parents went through a painful divorce that drove the family apart. Carla's sister married and moved to Florida, her brother went off to college, and her father became estranged. Feeling as if she had no one to turn to for support, Carla eventually found a cleaning job, working 28 hours a week at a local office building. Because she didn't make a lot of money, Carla hoped to cut costs by moving into a small apartment with her mother. She didn't work enough hours to have health insurance, but that didn't matter because Carla was seldom sick, nor was she the type to go to the doctor. "I don't trust them," Carla would say. "Everyone who goes to the doctor comes out sicker than when they went in!"

When Carla was 29, she experienced a deep pain inside her vagina. She decided it was minor "female problems" and believed it would eventually go away. For three months the pain persisted and worsened. Eventually, the pain became so great that Carla had to cut back her work hours from 28 to just 15 a week. By this time, she knew she would have to face her biggest fear and go see a doctor at the local health clinic.

The day of her doctor's appointment finally arrived. The examination room was cold and Carla felt embarrassed about having to undress. While being examined, she experienced a lot of pain, which made it difficult to concentrate and

listen to the doctor. After a few minutes, Carla knew something was wrong because the doctor stopped the examination abruptly and asked a nurse to come into the room. "What's happening?" Carla asked. Her physician, an imposing older man with a thick Middle Eastern accent, explained that he found what he believed was causing her pain—a tumor that was likely cervical cancer. "Cancer? How did I get this?" she asked him. The doctor said that the most likely cause was contact with HPV, a sexually transmitted disease, and that surgery was necessary to remove it. Upon hearing this, Carla's mind drifted off to thoughts about her intimate encounters with the few boyfriends she'd had when she was younger. It wasn't like she was promiscuous, but she never felt the spark she needed to get serious with someone.

Always having been a private person, Carla felt no need to inform her family or friends of her condition. They do not need to know, she thought. They will just worry, and besides, I don't want everyone judging me or knowing my business. Moreover, she could never tell her family or friends that she had sex before marriage. If people found out, they might consider her "la puta," or a loose woman. The doctor scheduled Carla for surgery the following week.

On the day of her procedure, Carla went to the hospital alone. She was afraid, but took comfort in her belief that the physician could remove the cancer and she would be fine. While on the operating table, however, Carla's doctor discovered that the cancer in her cervix had metastasized to the lymph nodes and was now much more serious. Hours later in recovery, Carla's doctor discussed the findings from her surgery and provided Carla with information about chemotherapy and radiation treatment options. Still groggy from the anesthesia, Carla did not understand these options or the outcome of her surgery. She only knew that the sound of the doctor's voice, confident and calm, made her feel safe and believe that she would be fine. Carla went home two days later. She told her mom it had been a small procedure and not to worry herself.

The following week, the doctor's office called and scheduled Carla for intensive chemotherapy and radiation therapy. In between treatments, Carla tried to remain steady at work. As days went by, however, her pain increased and it became more difficult to walk and perform her cleaning duties. Just 6 weeks after surgery, when she was too tired and weak to work, Carla's employer fired her. With no job and unable to walk without assistance, Carla asked her mother and older brother if they could assist her in going to her next appointment. "Appointment for what?" her mother asked. "For cancer," Carla replied. "Dios mío! You didn't tell me you had cancer," her mother exclaimed.

At the 8-week post-op appointment, Carla, her brother, and her mother waited anxiously in the tiny examination room. When the doctor entered, he suddenly became startled. "You have family? You didn't tell me you had family except for one sister in Florida," he said. "Yeah," Carla replied hesitantly. "This is my mom and my brother." The physician smiled and responded, "Okay then. Well I need to do a physical examination and must ask them to leave. I will invite them back in once I am finished. Is that okay with you?" Carla replied, "Yes." The examination took less than 10 minutes and was excruciatingly painful for Carla.

When Carla's family reentered the examination room, the physician asked, "Okay, what do you know about her condition?" "Not much," responded her mother. "She just told us this morning." Carla's brother said, "All I know is that she has cancer, and we don't know what type of cancer it is." The physician replied, "What she has is called cervical cancer." He went on to explain:

When I saw her initially, we did tests and discovered the cervical cancer. I decided to take her to the operating room and perform the surgery here. When I opened her, I found that the cancer had spread beyond the cervix to the lymph nodes. Because I found that the cancer had spread to the lymph nodes, I could not perform the surgery to remove the cancer because it would not help. I made the decision to close her up, and we gave her radiation and chemo weekly for six weeks. She was doing fine, but then started to complain about the pain in her abdomen. We did X-rays and found that the cancer had grown and spread beyond her cervix and lymph nodes, into her abdomen and around her lungs. Right now, she has what we call Stage IV, which is the highest and worst stage of cancer."

After a brief pause, the physician continued:

There is no cure for the disease at this stage. She has been under my care for the past two months and this is the first office visit I have had with her since she started the combined radiation and chemotherapy treatment, which I hoped would slow the cancer. When I attempted to perform a pelvic examination on her just now, I saw that the vagina was totally closed by the cancerous tumor. Therefore, the only hope we have for her right now is to continue the chemotherapy because I have given her all the radiation she can receive.

At this moment, Carla interrupted. "So, what are you telling me? Am I dying?" With sincerity in his eyes, the physician gently replied, "Your prognosis is serious. I am not going to lie to you. You are not dying right now, but unfortunately, the treatment you have received does not cure most of the time, which means most likely you will die from this cancer."

Holding on tightly to Carla, her brother asked, "So what are the options now? That's what I need to know." The physician responded, "The number one option now is to continue the chemo, or if she doesn't want chemo, we can refer her to hospice care." The physician explained that chemo works by inhibiting the growth of cancer cells, and that this type of treatment may help to extend Carla's life, but it will not cure her of the cancer. He also informed them that there are risks and side effects to chemo, which may increase Carla's discomfort. On the other hand, the physician told Carla and her family that hospice is a form of comfort care that manages pain and other symptoms.

"Hospice care," the brother said with inquisition. "Isn't that where you go when you're done, give up, and are basically ready to die?" he asked. Lowering his head, the physician replied, "That's correct, but it's also for people with life-limiting illnesses so that they can be as comfortable as possible for the time that remains." Carla began to weep. With her brother and mother close, Carla and her family knew the next few days would be difficult. She and her family would need to

get as much information as they could in order to make a decision on the limited options she had left.

Carla was deeply weary of carrying the burden of her illness alone. She notified her doctor that she no longer wanted chemotherapy and that she wished to pursue hospice care. Shortly after, a social worker called and helped Carla and her family find a local hospice center that could provide her quality in-patient care. While in the facility, Carla and her family learned that hospice care was not about dying, as they originally thought, but rather about living life to the fullest without mind-numbing pain. Carla spent the remainder of her days enjoying her family, eating her favorite foods, and listening to salsa music while envisioning herself dancing the night away.

RELEVANT CONCEPTS

Breaking bad news Family communication Hospice
Clinical communication Health literacy

DISCUSSION QUESTIONS

1. This chapter discussed a real-life case in which an uninsured, low literacy, terminally ill patient and her family members attempt to navigate a bad-news prognosis discussion and hospice care.
 - What do you believe was the greatest barrier to Carla's communication with her family? With her doctor?
 - What might health communication researchers contribute to help remedy this situation?
2. Explaining a terminal prognosis to a patient is perhaps one of the most difficult things a clinician has to do. How would you deliver this kind of bad news to a person like Carla? (Consider timing, literacy, available social support, and any other factors that might make a difference.)
3. Cancer, particularly incurable cancer, can feel stigmatizing to the person who has it.
 - How might Carla feel stigmatized in this story? How does it affect her?
 - Aside from cancer, what other diseases and health challenges might have a stigmatizing effect?
4. In this scenario, Carla's mother and brother knew very little about her diagnosis. It fell to the clinician to explain it to them. In your opinion, how well did he size up the situation and adapt his message to his listeners? What might he have done differently?
5. When compared to non-minority populations, minorities are more often diagnosed with late-stage illnesses that can lead to increased suffering.¹ In addition to these disparities, members of minority populations with health literacy challenges can experience a complex array of communication difficulties, including misunderstandings about their medical treatment and condition.² How does this play out in Carla's case?

NOTES

1. National Cancer Institute. (2016, May 13). *Cancer Health Disparities*. Retrieved from <http://www.cancer.gov/research/areas/disparities>.
2. National Cancer Institute. (2016, May 13).

SUGGESTIONS FOR ADDITIONAL READING

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