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ESSAY/PERSONAL REFLECTIONS

Now what? When information is too much

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Ms. Mable Jackson (pseudonym) was a 73 year old woman with widely metastatic breast cancer. I first met Ms. Jackson during an intensive care unit admission in January of 2009. She was comatose. Her thin body was rattled with cancer. Ms. Jackson died a few days after I met her. During the few days preceding her death, I had met her two sisters and her two daughters. Ms. Jackson carried the BRCA1 gene, which meant that her relatives were at an increased risk for both breast and ovarian cancers. Unfortunately, Ms. Jackson had not shared this information with her family. I first wanted to find out why she hadn't talked to her family about this genetic information. Her oncologist had met her only a few weeks before me, and the genetic information had come back a few days prior to the ICU admission. He hadn't yet had a conversation with her about the test results. Now, that I knew about her family's predisposition to specific cancers, what should I do with that information? Would her family want to know? Was it right for me to share that medical information of Ms. Jackson with her family? This was something that I struggled with during my time interacting with her family. I was never able to ask any of these questions to Ms. Jackson.

What if they didn't want to know this information? Did they have the right to know this information? Was I obligated to share this information with them? Would I be negligent if I didn't share this information with them? Who was going to follow up with the family to ensure that the information was understood? What about the possible harm that could come from the information? What about the possible harm that could come from not sharing this information? When should this information be revealed? I was not the doctor for any of the family members. In fact, I had only met the patient and her family a few days prior to her death.

During our last meeting prior to Ms. Jackson's death, I began a discussion with her family about Ms. Jackson's cancer and what are some things that cause this cancer. I brought up genetic risks factors for this cancer. When I brought up that some families have an increased risk of this cancer, each of those present wanted to know how that applied to them. I revealed the genetic information. Not one of the family members went to the doctor regularly and no one had ever had breast cancer screening. I encouraged each of the family members to follow up with breast clinic and gynecology clinic at the hospital. I made follow up appointments in the two clinics for each of the family members. Not one of the family members ever showed up for their appointments.

I still struggle with this case. I wonder if the information wound up providing more harm than good. I will not know the answer. But, this issue comes up often for me in my position as a palliative care physician. I encourage patients to share genetic risk factors with family members. Sometimes, the time from diagnosis to death is too short that this discussion never happens. Sometimes, patients do not want to share the information with family members. Doctors have an obligation to help people, even if those people are not their patients. However, information that is helpful to some may in fact be harmful to others. I am still not sure how to differentiate between the two in these very difficult situations.

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