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## An American Indian Patient Experience

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American Indian women in the Southwest United States experience higher ovarian cancer mortality rates compared to White women.<sup>1</sup> High rates of overall cancer mortality and morbidity are attributed to delays and obstacles in seeking and receiving cancer screening or care.<sup>2,3</sup> This commentary highlights several recommendations based on an American Indian ovarian cancer patient's experience during treatment and end-of-life care with the goal of improving care for other American Indian cancer patients.

On September 14, 2018, our mother, a 77-year-old American Indian woman, lost her battle with ovarian cancer. Our mother, like many other American Indians, had multiple comorbidities including anemia, congestive heart failure, asthma, type 2 diabetes, sleep apnea, obesity, and arthritis, among others. She was a widow, spoke English as a second language, had a 7<sup>th</sup> grade education, and had not been gainfully employed since 1963. Our mother's comorbidities and socioeconomic status no doubt played key roles in her care and experiences.

First, clinicians need to be prepared, forthcoming, and comfortable with imparting negative information; in doing so, they are adhering to the principle of respect for autonomy, one of the moral principles that apply to clinical practice.<sup>4</sup> My mother and our family knew that the diagnosis of cancer was serious and were looking to the experts for guidance and information. No matter how negative the diagnosis and prognosis, clinicians need to impart what they know about a patient's disease, its expected progression, and options for care to the patient and the family, including how to prepare for decisions that may need to be made. Furthermore, clinicians can better facilitate communication by identifying the preferences of the patients and family members on how to disclose bad news.<sup>5</sup> So much confusion and frustration on our part could have been minimized if the clinicians had just been straightforward with us. Something as simple as informing our family that bowel obstruction<sup>6</sup> is common in ovarian cancer patients would have been quite helpful. We also did not know the potential outcomes of malignant bowel obstruction and that percutaneous endoscopic gastrostomy (PEG) tube placements are a common treatment.<sup>7</sup> Perhaps, more

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importantly, we were not aware and were not told that this procedure would make our mother ineligible for further chemotherapy. Although our mother made her own medical decisions, she relied on us for questions, translations, and interpretations of what the health care providers were saying.

Second, we recognize that our medical care systems, especially emergency departments (ED), are understaffed, overwhelmed, and underfunded;<sup>8</sup> nonetheless, when dealing with a patient with a serious illness like ovarian cancer, every effort should be made to listen to the patient's concerns to obtain appropriate consultations. Through upholding clinical standards of care, the clinicians are adhering to the principles of beneficence and nonmaleficence.

On May 11, 2018 (a year to the day we are writing this), we took our mother to the local teaching hospital emergency department (ED) at 3:56 p.m. with complaints of shortness of breath, swollen ankles, and a distended abdomen. Our mother waited three and a half hours to be seen (one hour in the waiting area and two and a half hours in the exam room). At 12:30 a.m., our mother started vomiting, and she continued to do so throughout the night. We continuously called for a doctor and the nurse. The nurse did come in several times and we relayed our mother's continued vomiting and at 3:58 a.m., she brought in "a sandwich to settle your mom's stomach." The doctor did not come and despite hearing and seeing our mother's distress, a discharge was initiated.

Finally, at 6:15 a.m., 14 hours after presenting to the hospital, the gynecologic oncologist on call was finally paged, but only after the ED doctor finally came to our mother's room and personally witnessed the vomiting—which we had been reporting since shortly after midnight. After being seen by the oncologist, our mother was not discharged and was instead admitted for a gastric tube placement five days later on May 16, 2018. This is but one example of suffering our mother experienced while within a health care delivery system meant to offer timely care and treatment.

Third, the allowable reimbursements for hospice care need to be expanded; thereby, the health care system is adhering to the principle of justice. Several weeks later on June 6, 2018, our mother was referred for hospice care. Although our mother had Medicare, Medicaid, and Indian Health Service contract health coverage, and we selected a hospice based on recommendations from our local health clinic, my mother did not receive the end-of-life comfort care she needed and that we expected for her.

The hospice staff did not have direct access to my mother's medical records because they were not affiliated with the teaching hospital, so they were not fully familiar with her case. More importantly, they did not check her PEG tube (it was not "within our purview" we were told), even though we told them about the increasing abdominal distention and fluid seepage. The accumulating fluid was seeping from around the tube opening causing redness, an open flesh wound, and eventually an infection. Through repeated requests to hospice, a paracentesis was eventually authorized and performed; however, the worsening wound was still only being taken care of by the family. During the paracentesis, repeated requests were made to check the wound and to check the infection. We were told that, "the procedure was not authorized by a physician and could therefore not be performed" and that there was

“nothing that could be done.” This experience was disheartening and totally contradictory to the ethos of health care delivery, medical ethics, and the Hippocratic Oath.<sup>9</sup> Our mother ended up in the university teaching hospital ED the next day (June 29, 2018) because of the infection.

Fourth, oncologists should provide care through end-of-life, thereby adhering to the principles of justice and beneficence. Although our mother received state-of-the-art care while her cancer could be treated with chemotherapy, as soon as she was beyond chemotherapy (as of June 5, 2018), the oncologists, residents, and nurses all disappeared. As the cancer progressed, the multifaceted decreases in physical, mental, emotional, spiritual, and social functioning were pronounced and the family was left to its own devices. During this time, when our family needed medically trained professionals the most, these professionals were completely absent. Hospice care provides weekly home visits with a nurse, social worker, and chaplain, and although these are appreciated and helpful, they are not enough. As caregivers for our mother, we were responsible to administer pain medications to make our mother comfortable. Physicians<sup>10</sup> and pharmacists<sup>11</sup> receive extensive training in pain management. Yet we, untrained family caregivers, were tasked with evaluating and treating our mother’s pain and given access to and asked to administer numerous medications including opioids such as oxycodone and morphine.

We understood the gravity of our mother’s diagnosis and we toiled day and night to make her comfortable. The end of her life came, but the loss of our mother’s dignity lingers. The effect of the indifferent and inadequate care our mother received made us question the health care system. These experiences underscore that low levels of health care literacy, distrust in the health care delivery system, and dissatisfaction with clinicians are further challenges for American Indians.<sup>12,13,14</sup> As long as inequity exists in health care systems, patients like our mother will experience loss of autonomy, avoidable harm, and injustice.

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