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# Social Factors Affecting Treatment of Cervical Cancer: Ethical Issues and Policy Implications

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# Social Factors Affecting Treatment of Cervical Cancer

## *Ethical Issues and Policy Implications*

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Health care in the United States has become a privilege rather than a right. Patients who have the greatest need are the ones most likely to be denied this privilege. Despite recent advances in disease detection and treatment, many patients do not receive even the bare minimum of care. The high complexity of the health care system in the setting of patients with low levels of health literacy significantly affects the ability to seek and receive treatment in a timely fashion. In addition, lack of insurance, transportation, and social support further complicate access to care. To truly provide a standard of care to all patients, regardless of resources, our health care system must evolve to

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address the needs of the population. In this paper, we report a tragic case where social factors affected the outcome of a single mother with advanced cervical cancer.

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### **THE PROBLEM**

Despite the arrival of new human papillomavirus (HPV) vaccines, cervical cancer will remain a serious health threat for at least 50 years. In 2007, the American Cancer Society projects 11,150 new diagnoses and 3,670 deaths from cervical cancer.<sup>1</sup> Socioeconomic status, access to care, and lack of health insurance coverage correlates with delay in diagnosis, advanced stage, and impaired survival.<sup>2–6</sup> Financial concerns are compounded by health care structures that can impede a woman's timely progress to the appropriate provider and may limit her access to the vaccine.<sup>7</sup>

The Centers for Disease Control and Prevention estimate more than two billion dollars are spent annually in the United States for the treatment of cervical cancer—on a disease that is preventable and often curable.<sup>8</sup> The need to address missed opportunities for intervention is clear, yet the scope of the problem can be overwhelming.<sup>9</sup> The following case highlights failures of multiple social and health care systems to provide adequate care for a single mother with the

diagnosis of advanced cervical cancer. Certain details were altered to protect the anonymity of the patient presented.

### **THE CASE**

Our patient was a 42-year-old African-American woman initially seen in the emergency department at a county hospital for complaints of back pain. At that time, she was diagnosed with a urinary tract infection and discharged to her home. Over the next year and a half, she had nine additional emergency room visits to multiple emergency rooms for nonspecific complaints, including abdominal or pelvic pain, constipation, and urinary incontinence. Follow-up appointments were suggested and scheduled via the emergency room, but the patient did not keep these appointments. Because she had limited financial resources, our patient was given information in the emergency department regarding necessary paperwork and documentation to receive county health coverage. However, she could not complete the paperwork over the course of 15 months.

In her tenth presentation to the emergency room for abdominal pain, a pelvic examination was performed but was limited secondary to patient discomfort. The emergency physician visualized what was suspected to be “the uterus”



at the vaginal introitus, and she was referred to the gynecology clinic for evaluation of “uterine prolapse.”

During her visit to the gynecologic clinic at the same hospital less than 2 weeks later, a large mass was discovered on the cervix during pelvic examination. A biopsy confirmed squamous cell carcinoma, and the patient was referred to gynecologic oncology. Before her appointment in the gynecologic oncology clinic and after a computed tomography scan, our patient developed back pain and mental status changes, presented to the emergency room, and was admitted with fever, bilateral hydronephrosis, metabolic acidosis, and renal failure. She received antibiotics and underwent bilateral percutaneous nephrostomy tube placement. During her admission, pelvic examination confirmed a 6-cm lesion involving the parametria, giving her a diagnosis of a stage 3b cervical cancer, which, although advanced, was still potentially curable. After 10 days, the acidosis resolved. The diagnosis and necessary treatment were discussed with her, and she was discharged with applications for Medicaid and supplemental financial assistance for treatment at a nearby major cancer center.

Over the next 4 months, our patient presented to the county gynecologic oncology clinic every third week. Each time, she presented with the collected information she thought she needed to obtain county-sponsored health insurance and financial assistance for treatment at the cancer center. Each time, she did not have the necessary paperwork completed, and the required information was reiterated. Although the patient had a 9th-grade education, she had no concept of the specific information and documentation she needed

to obtain assistance at the governmental agencies and no reliable transportation. Furthermore, she was unable to walk for more than a few feet due to pain and weakness, necessitating the use of a wheelchair. Four months after her percutaneous nephrostomy tubes were placed, she qualified for emergency Medicaid.

Within 1 week of receiving Medicaid, our patient had an appointment with radiation oncology at the cancer center. Staging radiography was repeated and magnetic resonance imaging revealed new disease in her pelvic lymph nodes and persistent bladder invasion. The treatment plan was formulated in a multidisciplinary clinic for concomitant chemo-radiation therapy.

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*Approximately 90 million American adults lack the health literacy needed to successfully navigate our increasingly complicated health care system.*

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With transportation assistance via the American Red Cross, she completed her external radiation therapy over the recommended 5-week interval. However, she missed two chemotherapy appointments during these treatments due to reported pain and lack of child care. She was responsible for the care of many individuals, including her mother, who was paralyzed from a cerebrovascular accident. In addition, she was the caregiver for her sister's four children, her own child, and a grand-niece.

After external beam radiation treatment, our patient was scheduled for two intracavitary brachy-

therapy applications. The first placement was delayed when she was evicted from her home and missed her appointment. At the rescheduled appointment, her physical examination revealed large ileovaginal, rectovaginal, and vesicovaginal fistulae, possibly the result of tumor response. Intracavitary radiation was aborted due to infection and fistulae. Her clinical situation was reviewed at a multidisciplinary conference, and it was felt that an ileal diversion was necessary before continuing with radiation therapy. Her physicians believed that intensity-modulated radiation therapy would be needed to complete the radiation treatment.

A diverting ileostomy was performed for relief of fistula-related symptoms. A radiation treatment plan was designed. However, 2 weeks after surgery, she experienced a small bowel obstruction requiring resection and revision of her ileostomy. Given treatment delay due to fistulae, extensive disease burden, and surgical complications, her case was presented again to the multidisciplinary conference where it was determined that further radiation therapy would compound her morbidity without a chance of cure. Although the patient was advised of her grim prognosis and reassured that she would continue to be cared for, she noted in conferences with the social worker that she felt “optimistic about her recovery.”

Over the next 5 months, our patient had three emergency room visits to the same hospital for nausea, dehydration, and electrolyte imbalance. One of these visits resulted in hospital admission. Pain control continued to be a challenging issue, often because of her inability to refill prescriptions before she exhausted her supply of medication. As a result, she presented to the clinic and emergency room for



intravenous narcotic administration. She was repeatedly offered hospice care but was not ready to accept this option.

Ultimately, our patient was admitted to the hospital with vaginal bleeding and hypotension. Again, end-of-life care was discussed, but she did not feel ready to make a decision regarding her preferences for resuscitation and further treatment. She experienced cardiopulmonary arrest and was intubated, as there was no Do Not Resuscitate order in her medical record. Care was withdrawn after her grim prognosis was discussed at a family conference. She expired 13 months after her original diagnosis and 27 months after her first visit to the emergency room.

## LESSONS LEARNED

As is often the case in situations with tragic outcomes, the “system” failed our patient at several levels, and no one factor was entirely responsible for this system failure.<sup>10</sup> The clinical and demographic characteristics of this unfortunate woman clearly had an effect, in addition to the lack of comprehensive care she received during her visits to the emergency room. The global challenges that uninsured patients face, further compounded by our complicated medical care system, clearly influenced her clinical outcome.

Our patient exhibited a low level of health literacy, or “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.”<sup>11</sup> This does not necessarily mean that the person in question is not functionally literate in day-to-day activities, merely that given their particular situation, including cultural and linguistic barriers, quotidian burdens, illness constraints, and the patient’s home situation, their capacity to wrangle their way suc-

cessfully through the health care system is compromised. Approximately 90 million American adults lack the health literacy needed to successfully navigate our increasingly complicated health care system.<sup>11</sup>

Several studies report that low or limited health literacy is an independent risk factor of worse health outcomes, independent of race and education.<sup>12–17</sup> In one follow-up study, it was found that those with limited literacy had approximately twice the rate of death as those with adequate literacy.<sup>15</sup> For these reasons we believe that addressing the unnecessary complexity of our health care system has become an ethical and a health policy imperative.

Our patient had not undergone Papanicolaou test screening for more than 10 years. She was unaware of the importance this test played in the early detection of cancer. Despite continued advances in the screening process, many women do not realize the need for this test. Low health literacy has also been shown to correlate with less frequent use of preventive health services and less likelihood of receiving follow-up care.<sup>18</sup> Even women who undergo Pap tests regularly can have a poor understanding of the consequence of screening, leading to follow-up delays after abnormality detection.<sup>19</sup>

For patients receiving care in the emergency room, misperceptions regarding specific tests that were performed may lead to the assumption that a Pap test was performed. In a study of an emergency department in Cincinnati, 60 of 81 women who underwent pelvic examination believed that they received a Pap test. Of those 60 women, 17 (28%) understood that the Pap test screened for cervical disease.<sup>20</sup>

Access to cancer screening and treatment can be affected by multiple

social factors. Our patient struggled with transportation issues throughout the course of her disease. A majority of her trips to the emergency room were made via ambulance. Once diagnosed, she missed appointments for diagnostic studies, chemotherapy, and symptom control. In addition to transportation difficulties, she was overburdened by family responsibilities. In a study of 146 women undergoing treatment for cervical cancer, a correlation was found between lack of cervical screening and perception of lack of family support in times of illness.<sup>21</sup> Not only was her death significant because of the usually curable nature of cervical cancer, but also because of the loss of a person who had been the main caregiver for seven other family members.

Our patient experienced a delay in diagnosis due to the fact that her basic medical care was provided in the emergency setting, which is a common phenomenon among low income patients.<sup>22,23</sup> The lack of continuity and focus on acute symptoms allowed her more subtle complaints to go unaddressed. Ideally, the emergency room serves acute patients, but this emergency room failed in the delivery of quality health care. However, as the health care system becomes less accessible, diagnosis and treatment of chronic disease become more of an emergency room issue.<sup>22,23</sup> This leads to overcrowding, which can affect overall patient care and prognosis.<sup>24</sup> In Texas in 2002, primary care-related issues made up 56% of the chief complaints in major emergency rooms.<sup>25</sup>

Lack of insurance coverage was the single most important factor explaining disparities in access to care in a recent study.<sup>26</sup> In 2006, 14.5% of all Americans were uninsured, while in Texas, this proportion is 25.1% and is 32% in the





county (population 3.9 million) that includes Houston.<sup>25</sup> Patients with insurance coverage are less likely to report unmet medical needs and more likely to have a regular medical provider.<sup>26</sup> In a cross-sectional study of cancer patients, Guidry et al<sup>27</sup> noted that patients reported significant out-of-pocket costs for cancer treatment due to lack of insurance coverage.

The cost of chemo-radiation, the treatment for advanced disease, reaches \$110,000. This monetary value does not reflect the costs that are associated with frequent visits to a treatment center, including transportation, child or elder care, and time lost from work. When the costs of radiologic workup, emergency room visits, and hospitalizations for symptom management or renal failure are considered, the total cost of advanced cervical cancer can reach \$500,000. Comparatively, the cost of a radical hysterectomy, the curative procedure for stage I disease, is approximately \$45,000 (UTMDACC, Department of Gynecologic Oncology Business Office. Personal communication, 2007). This reduction pales in comparison to the relatively inexpensive annual examination with screening Pap test, which costs the patient \$250, or the HPV vaccine, which costs approximately \$360 (UTMDACC, personal communication, 2007).

As demonstrated in this case, patients without health insurance have multiple hurdles to overcome. Extensive paperwork and documents necessary to demonstrate a patient's financial need can be overwhelming to patients without a stable home, who do not speak English, have limited education, and who are already in poor health.<sup>28,29</sup> Furthermore, after diagnosis, a patient may never receive therapy for cervical cancer. Prolonging timely radiotherapy treatment

due to missed appointments can result in poor clinical outcomes.<sup>30</sup> Identification of these issues is not only a quality-of-care issue but a fiscal concern.

If health care is essential to life, who has the responsibility to provide care to those who cannot afford it? We are already "paying" for the lack of universal coverage, given the current high cost of insurance and federal programs. Greater coverage, resulting in the utilization of preventive care, has the potential to reduce medical care costs in the long run.<sup>9</sup> The thought of disparities as deviation from the standard of care, rather than discrimination or "unfortunate circumstances," is necessary to bring this issue to the forefront of the political agenda. With political will, policies can be developed to alleviate factors that contribute to disparities.<sup>9</sup>

This is not just an issue of providing programs supporting the indigent patient, but resolving the complexity of the process. Presently, the American health care system typically assumes a high level of health literacy, despite the fact that one in three users has low health literacy. In addition, our health care system has been shown to be unnecessarily complex.<sup>16</sup> It is not just an issue of assisting with treatment cost, but relieving other social barriers that prevent the patient from getting to the treatment facility. Finally, it is not just an issue of getting the patient to providers, but educating providers on the needs of indigent patients to ensure therapy completion and disease survival.<sup>9</sup>

Our goal should be, rather than deviating from the standard of care, advocating for the policy changes necessary to relieve barriers to care and eliminate the disparities evident in our health care system. These policy changes should include, but not be limited to, re-

adjusting the standard of care from assuming high levels of autonomy, financial independence, health literacy, and familial support, to one in which patients are assumed to be lacking in these categories.

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