



## FOCUS ISSUE – Celebrate Diversity with the AUA

### Medical Ethics and Urological Surgery



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The urological community has come together to promote diversity, equity and inclusion in our workforce in support of societal efforts to condemn systemic racism and bias. Like much of the history of medicine, the history of urology is stained by events in which medical professionals capitalized on systemic racism and bias to take advantage of the most vulnerable among us. This article will review 2 infamous historical examples and frame them within the context of 4 principles of medical ethics: autonomy, beneficence, nonmaleficence and justice (see figure).<sup>1</sup> In this article, we hope to remind *AUA News* readers about these experiments, consider some ethical issues surrounding these experiments, and explore how we can use tools such as shared decision making to inform contemporary urological practice.



Figure. The 4 pillars of biomedical ethics. Adapted from Beauchamp and Childress.<sup>1</sup>

The surgeon J. Marion Sims developed his technique and instruments for vesicovaginal fistula (VVF) repair in 19th century Alabama through experimental surgery on enslaved Black women, 3 of whom we know by name: Anarcha, Betsey and Lucy.<sup>2</sup> Although other contemporary surgeons also reported successful VVF repair, it was Sims who gained notoriety and fame for the discoveries he made in a makeshift hospital behind his Alabama home.<sup>2</sup> He went on to establish Woman’s Hospital in New York, to be lauded as the “father of gynecology,” and to become the first U.S. physician to have a statue erected in his honor. That statue stood in New York City’s Central Park from 1894 until it was removed in 2018.<sup>3,4</sup>

In the 1950s, a prominent researcher at Columbia, in New York City, Perry Hudson, studied the diagnosis and treatment of prostate cancer in asymptomatic men. However, he found it difficult to recruit men from his medical practice who would be willing to undergo the open prostate biopsies, prostatectomies, castration and hormone therapy that his approach required. Therefore, Hudson decided to recruit his experimental subjects in the area of New York City called the Bowery, home to many vulnerable people suffering from homelessness, alcoholism, and other mental and physical impairments.<sup>5,6</sup> While the men did in one sense volunteer for

the experiments, many were implicitly coerced by the opportunity for food and shelter. Once enrolled, men could not easily withdraw consent, as their meal tickets were only returned after they participated in treatment appointments.<sup>5,6</sup> Hudson published his work, sometimes called the “Bowery” experiments, in leading medical journals through the 1950s and 1960s.<sup>7,8</sup>

A stepwise approach using 4 principles of medical ethics can be helpful in processing these historical accounts. First, consider autonomy, the right of people to retain control over their own bodies.<sup>1</sup> Two conditions are needed for autonomy: persons must have the capacity for self-government, and the decision must be free from external constraints.<sup>1</sup> Even though Sims uses the word “consent,” Anarcha, Betsey and Lucy (and the other women whose names we do not know) were enslaved women. They had no autonomy; they were given to Sims by their owners “for experiment.”<sup>2</sup> Although men in the Bowery series are said to have volunteered, many may not have had the mental capacity, due to mental illness and substance abuse, to give consent. Moreover, extrinsic factors such as the need for food and shelter may have significantly influenced their decision to participate in the study.

Next, consider beneficence, the desire to improve the condition of patients and society, and nonmaleficence, which implies doing no harm.<sup>1</sup> Sims performed surgeries in a preanesthetic era hoping for medical breakthroughs. While one might want to see an element of beneficence, seeing as these women were afflicted with a devastating complication of pregnancy, we should consider that Anarcha underwent 30 surgeries over 4 years, even as Sims’ peers questioned and abandoned him.<sup>2</sup> Anatomical cure drove his actions, not the well-being of Anarcha and the other women.<sup>2,4,9</sup> When we consider nonmaleficence, we must recall that the

women suffered significant harm from the surgeries.<sup>2</sup> Sims describes that after one operation, “Lucy’s agony was extreme ... and I thought that she was going to die ... It took Lucy 2 or 33 months to recover entirely from the effects of this operation.”<sup>2</sup> In the Bowery series, it is clear from today’s knowledge of prostate cancer that few if any of the men who volunteered for the experiments derived benefit from incidentally diagnosed prostate cancer, while countless men faced the morbidity of prostatectomy and castration. On a societal level, the Bowery experiments were the first of many steps toward screening and early detection of prostate cancer, which have reduced the mortality rate for the disease but have also caused morbidity among men whose lives may not ever have been shortened by untreated disease.<sup>5</sup>

And finally, consider justice—the equitable distribution of social benefits.<sup>1</sup> In the context of slavery, justice is unfathomable. Considering justice for the young women, born into slavery and all of its evils and forced to undergo 4 years of repeated surgical experimentation, gives us a clear answer: there was no justice for Anarcha, Bestey or Lucy, and the countless other women. The overwhelming benefit of their suffering was afforded to Sims, who soon after his discovery relocated to New York, where he achieved fortune and fame. Similarly, justice in the context of the Bowery’s vulnerable men is inconceivable. These men did not receive the benefits of the research that was performed on them. Hudson and his peers capitalized on these men’s misfortune in order to arrive at conclusions that would largely be applied for the benefit of men with greater means.

While the implications of these historical events in our urological history are many, one thing is clear: in our practice and research we should strive always to consider autonomy, nonmaleficence,

beneficence and justice. It may help if we can engage patients and participants in the decision making process. Informed consent is not enough. Shared decision making has emerged as a process to engage patients in their medical decisions. It balances the best available medical evidence with the preferences and values of the patient.<sup>10</sup> We can ask clarifying questions to ensure that autonomy is present, that

patients feel they understand and can expect potential benefits and harms to treatment, and finally, that individuals feel that they have equitable and holistic care. ♦

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