



NORTHEASTERN UNIVERSITY  
LAW JOURNAL

# Extra Legal

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## Informed Consent: A Right Essential for All, Afforded to Few

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### **I. Introduction**

Many African-Americans in the United States receive neither the adequate cancer prevention and detection services nor the most appropriate treatment when faced with a cancer diagnosis.<sup>1</sup> This article proposes that an underlying factor influencing the inequality of treatment and care is the negative predisposed stereotypes and biases many practitioners have towards lower income minorities, particularly African-Americans. These predisposed stereotypes and biases can result in incomplete disclosure regarding an individual's diagnosis, treatment, and monitoring, among other things. This article arrives at the conclusion that the lack of informed consent has played an important role in the health inequity between minorities of color and people who identify as White.

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<sup>1</sup> JOHN A. CAPITMAN, SARITA BHALOTRA & MATHILDA RUWE, CANCER AND ELDERLY OF COLOR: OPPORTUNITIES FOR REDUCING HEALTH DISPARITIES 5 (2005).

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## **II. What is Informed Consent?**

The duty of informed consent is the ideal process of promoting the type of thoughtful and transparent communication between a patient and his doctor that permits the patient to realistically and objectively balance the benefits and risks of a proposed course of treatment.<sup>2</sup> The doctrine emphasizes patient autonomy as its principal value, highlighting the importance of providing patients with the necessary medical information to make a treatment decision that is fully informed and in accordance with the patient's beliefs and concerns.<sup>3</sup>

In the case of *Canterbury v. Spence*,<sup>4</sup> the Court of Appeals for the D.C. Circuit held that a physician has a duty to communicate the specific information that a patient needs to make an informed decision.<sup>5</sup> The *Canterbury* Court rejected the position that a physician's duty was limited to what prudent physicians disclosed in similar circumstances.<sup>6</sup> Instead, the Court found that the obligation to disclose and the scope of disclosure originate not from a medical community standard, but from the patient's right of self-determination.<sup>7</sup> The patient must possess enough information to make an intelligent decision for that right to be exercised effectively.<sup>8</sup> Therefore, the scope of the physician's duty requires, “disclosure of information that the patient would find material to making a treatment decision, to weighing the risks associated with having or not having the treatment, and to decide on any alternative treatment.”<sup>9</sup>

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<sup>2</sup> *Id.*

<sup>3</sup> *Id.* at 205–06.

<sup>4</sup> 464 F.2d 772 (D.C. Cir. 1972).

<sup>5</sup> *Id.* at 781; see Linda P. McKenzie, *Federally Mandated Informed Consent: Has Government Gone Too Far?*, 20 J.L. & HEALTH 267, 271 (2007).

<sup>6</sup> *Canterbury*, 464 F.2d at 783–84; see McKenzie, *supra* note 5.

<sup>7</sup> *Canterbury*, 464 F.2d at 780–81; see McKenzie, *supra* note 5.

<sup>8</sup> *Canterbury*, 464 F.2d at 786; see McKenzie, *supra* note 5.

<sup>9</sup> See McKenzie, *supra* note 5.

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The *Canterbury* Court held that there are two occasions where a doctor holds the privilege not to disclose.<sup>10</sup> The first instance is in an emergency situation where a patient is incapable of consent.<sup>11</sup> The second occurrence is where the disclosure may be so harmful to the patient that it is medically “contraindicated.”<sup>12</sup> The second exception permits discretion for the physician to decide what is in a patient's best interests to know, and to modify disclosure to the patient's unique condition.<sup>13</sup>

### **III. History of Informed Consent & the Developing Trend**

For much of this country's medical history, doctors paternalistically determined what they believed to be the suitable course of treatment for their patients without their input.<sup>14</sup> This was especially true for African-Americans who were presumed to lack the intelligence or competence to make reasonable decisions for themselves or their own health.<sup>15</sup> This presumption still exists today.<sup>16</sup>

Over the years, courts and state legislatures have combined efforts to create two prevailing requirements for informed consent.<sup>17</sup> These requirements include “the historical requirement that physicians obtain patients' [written] consent before proceeding with treatment, and the more recent

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<sup>10</sup> *Canterbury*, 464 F.2d at 788; see McKenzie, *supra* note 5.

<sup>11</sup> *Canterbury*, 464 F.2d at 788–89; see McKenzie, *supra* note 5.

<sup>12</sup> *Canterbury*, 464 F.2d at 789; see McKenzie, *supra* note 5; see also *Contraindication*, MEDLINE PLUS, <http://www.nlm.nih.gov/medlineplus/ency/article/002314.htm> (last updated Jan. 21, 2013) (defining “contraindication” as a specific situation in which a drug, procedure, or surgery should not be used because it may be harmful to the patient).

<sup>13</sup> *Canterbury*, 464 F.2d at 789; see McKenzie, *supra* note 5.

<sup>14</sup> Amanda McMurray Roe, *Not-So-Informed Consent: Using the Doctor-Patient Relationship to Promote State-Supported Outcomes*, 60 CASE W. RES. L. REV. 205, 205–06 (2009).

<sup>15</sup> See Melissa Welch, *Care of Blacks and African Americans*, in CROSS-CULTURAL MEDICINE 29, 30 (JudyAnn Bigby ed., 2003).

<sup>16</sup> See John F. Dovidio & Susan T. Fiske, *Under the Radar: How Unexamined Biases in Decision-Making Processes in Clinical Interactions Can Contribute to Health Care Disparities*, 102 AM. J. PUB. HEALTH 945, 948 (2012) (“Research on medical decision-making shows that physicians recommend more advanced and potentially more effective medical procedures (coronary bypass surgery) for White than for Black patients, and this disparity occurs because physicians assume that Black patients are less educated and less active.”).

<sup>17</sup> Roe, *supra* note 14, at 209.

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requirement that physicians disclose such information to patients as will enable them to participate knowledgably in making decisions about treatment.”<sup>18</sup>

In various states, legislators have enacted more specific informed consent statutes.<sup>19</sup> These statutes have transpired mainly to address perceived disconnects in communication between physicians and their patients, and the concern that practitioners are simply not providing their patients with all of the necessary information for certain procedures.<sup>20</sup> Critics of the recently developed informed consent statutes for specific procedures argue that they seem to have confused the traditional intent of informed consent.<sup>21</sup> These statutes instruct doctors to provide particular disclosures about certain procedures rather than promoting autonomous choice for their patient.<sup>22</sup>

#### **IV. History of Health Inequality**

When comparing African-Americans and Whites born in 2001, White men were predicted to have an additional 7 years of life, and women an additional 5 years.<sup>23</sup> The age adjusted mortality rate for Whites was 55% of the African-American rate.<sup>24</sup> Major contributions to these trends were cancer disparities.<sup>25</sup> In 2004, the National Cancer Institute (“NCI”) found that African-American men and women have 40% and 20% higher death rates from cancer combined than do White men and women.<sup>26</sup> African-Americans also tend to face higher mortality from liver, stomach, and cervical cancers and experience later stages of diagnosis and shorter survival periods compared to Whites.<sup>27</sup>

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<sup>18</sup> Roe, *supra* note 14, at 209.

<sup>19</sup> Roe, *supra* note 14, at 209.

<sup>20</sup> Roe, *supra* note 14, at 209.

<sup>21</sup> Roe, *supra* note 14, at 206.

<sup>22</sup> Roe, *supra* note 14, at 206.

<sup>23</sup> CAPITMAN, BHALOTRA & RUWE, *supra* note 1, at 14.

<sup>24</sup> CAPITMAN, BHALOTRA & RUWE, *supra* note 1, at 14.

<sup>25</sup> CAPITMAN, BHALOTRA & RUWE, *supra* note 1, at 15.

<sup>26</sup> CAPITMAN, BHALOTRA & RUWE, *supra* note 1, at 15.

<sup>27</sup> CAPITMAN, BHALOTRA & RUWE, *supra* note 1, at 15.

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Some studies have found significant connections between minorities' medical care and certain structural barriers, cultural manifestations, and systemic institutional discrimination.<sup>28</sup>

### ***A. Henrietta Lacks***

*“But I always have thought it was strange, if our mother cells done so much for medicine, how come her family can’t afford to see no doctors? Don’t make no sense. People got rich off my mother without us even knowin about them takin her cells, now we don’t get a dime.”<sup>29</sup>*

The exposure of African-Americans’ failure to be properly disclosed about the doctrine of informed consent and its resulting consequences began with Henrietta Lacks. Some civil rights activists consider Emmitt Till as “the sacrificial lamb” for the awakening of the Civil Rights movement.<sup>30</sup> In regard to the medical field, I consider the story of Henrietta Lacks as the commencement of awareness for minority patients to hold practitioners liable for failing to obtain informed consent.

Loretta Pleasant, historically referred to as Henrietta Lacks, Helen Lane, or HeLa,<sup>31</sup> died in 1951 from cervical cancer.<sup>32</sup> Just months before her death, doctors cut cells from a tumor in her cervix without her consent.<sup>33</sup> Before and around this time, scientists attempted to keep human cells alive in culture for decades, but the cells would eventually die.<sup>34</sup> To the contrary, Henrietta Lacks’

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<sup>28</sup> Alina M. Perez & Kathy L. Cerminara, *La Caja De Pandora: Improving Access to Hospice Care Among Hispanic and African-American Patients*, 10 HOUS. J. HEALTH L. & POL’Y 255, 258 (2010).

<sup>29</sup> Deborah Lacks, *Deborah’s Voice*, in REBECCA SKLOOT, *THE IMMORTAL LIFE OF HENRIETTA LACKS* 9 (1st ed. 2010).

<sup>30</sup> See CLENORA HUDSON-WEEMS, *EMMETT TILL: THE SACRIFICIAL LAMB OF THE CIVIL RIGHTS MOVEMENT* (AuthorHouse, rev. ed. 2006).

<sup>31</sup> *THE IMMORTAL LIFE OF HENRIETTA LACKS*, *supra* note 29, at 1 (“HeLa [is] the code name given to the world’s first immortal human cells...”).

<sup>32</sup> *THE IMMORTAL LIFE OF HENRIETTA LACKS*, *supra* note 29, at 3.

<sup>33</sup> *THE IMMORTAL LIFE OF HENRIETTA LACKS*, *supra* note 29, at 1.

<sup>34</sup> *THE IMMORTAL LIFE OF HENRIETTA LACKS*, *supra* note 29, at 1.

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were different in that they reproduced an entire generation of cells every twenty-four hours, and they never stopped.<sup>35</sup> Henrietta's cells became the first immortal human cells ever grown in a laboratory.<sup>36</sup>

Henrietta's cells are a significant part of historical research into the genes that cause cancer and the genes that suppress it.<sup>37</sup> Her cells helped create drugs and medicine for treating Parkinson's disease, hemophilia, leukemia, and influenza.<sup>38</sup> They have also been used to study human longevity, sexually transmitted diseases, lactose digestion, appendicitis, and mosquito mating.<sup>39</sup> In the case of Henrietta Lacks, the doctors simply failed to obtain her consent. Presently, the issue of doctors failing to obtain informed consent is very subtle and simultaneously more common. Often doctors obtain consent for suggested procedures, but inadequately inform their patients of satisfactory cancer prevention and detection services or the most appropriate treatment.<sup>40</sup> Hence, they are not accurately obtaining informed consent because the patients have not been justly informed.

### ***B. Holding Doctors Accountable***

There is support for the idea that unintentional bias emerges in medical encounters with minorities of color, which leads to disproportionate health care.<sup>41</sup> A report by the Institute of Medicine ("IOM") and the National Healthcare Disparities Report concluded that a major factor that may link the disparity to health care treatment is physicians' inadvertent behavior.<sup>42</sup> In other words, the respect or lack thereof for cultural differences might have an unintentional effect on passive

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<sup>35</sup> THE IMMORTAL LIFE OF HENRIETTA LACKS, *supra* note 29, at 1.

<sup>36</sup> THE IMMORTAL LIFE OF HENRIETTA LACKS, *supra* note 29, at 1.

<sup>37</sup> THE IMMORTAL LIFE OF HENRIETTA LACKS, *supra* note 29, at 1.

<sup>38</sup> THE IMMORTAL LIFE OF HENRIETTA LACKS, *supra* note 29, at 1.

<sup>39</sup> THE IMMORTAL LIFE OF HENRIETTA LACKS, *supra* note 29, at 1.

<sup>40</sup> See Dovidio & Fiske, *supra* note 16, at 948.

<sup>41</sup> THE IMMORTAL LIFE OF HENRIETTA LACKS, *supra* note 29, at 18.

<sup>42</sup> THE IMMORTAL LIFE OF HENRIETTA LACKS, *supra* note 29, at 17–18; Dovidio & Fiske, *supra* note 16, at 949.

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prejudices and biases of doctors.<sup>43</sup> Indicators of contemptuous prejudices may appear in inferior treatment, passive neglect, less active intervention or unnecessary technological procedures.<sup>44</sup>

Practitioners' inexperience with engaging race and ethnicity differences complicates the uncertainties of medical procedures and occurrences.<sup>45</sup> Doctors oftentimes make stereotypical inferences derived from a patient's ethnicity or race.<sup>46</sup> With this perspective, physicians tend to rely too heavily on stereotypes and can forget to address all the critical issues.<sup>47</sup> This results in an inadequate presentation and explanation to the patient of material information that is due under the doctrine of informed consent. Supporters of this theory found that some physicians carry negative views of African-Americans and underprivileged patients, which leads to less time and fewer patient-practitioner encounters.<sup>48</sup> Less time and fewer interactions may result in an incomplete disclosure of the patient's rights to sufficient care and treatment.

Another study was published by the American Journal of Public Health, which found that two-thirds of doctors held unconscious racial biases towards their patients.<sup>49</sup> The researchers say the results provide evidence that racial bias can have a negative impact on the quality of the doctor-patient relationship and the way medical care is delivered.<sup>50</sup> It supports the idea of a link between racial stereotypes and biases taking place in doctor-patient relationships.<sup>51</sup> In fact, yet another study found that practitioners have more negative implicit attitudes toward African-Americans than

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<sup>43</sup> THE IMMORTAL LIFE OF HENRIETTA LACKS, *supra* note 29, at 18.

<sup>44</sup> Dovidio & Fiske, *supra* note 16, at 947.

<sup>45</sup> See Dovidio & Fiske, *supra* note 16, at 947.

<sup>46</sup> Dovidio & Fiske, *supra* note 16, at 948.

<sup>47</sup> See Dovidio & Fiske, *supra* note 16, at 948.

<sup>48</sup> Dovidio & Fiske, *supra* note 16, at 948.

<sup>49</sup> Jessica Cumberbatch Anderson, *Racial Bias Among Doctors Linked to Dissatisfaction with Care, Report Says*, HUFFINGTON POST (May 3, 2012, 10:06 AM), [http://www.huffingtonpost.com/2012/05/03/racial-bias-doctors\\_n\\_1472281.html](http://www.huffingtonpost.com/2012/05/03/racial-bias-doctors_n_1472281.html).

<sup>50</sup> "Unconscious" Racial Bias Among Doctors Linked to Poor Communication with Patients, *Dissatisfaction with Care*, MED. NEWS TODAY (Mar. 16, 2012, 1:00 AM), <http://www.medicalnewstoday.com/releases/242975.php>.

<sup>51</sup> *Id.*

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toward Whites.<sup>52</sup> The more negative their implicit attitudes, the less likely they were to recommend a certain drug for African-American patients.<sup>53</sup> Further studies show that African-American patients are less likely than White patients to be recommended for surgery for oral cancers.<sup>54</sup> African-American patients, compared to White patients, are also more likely to be recommended for and to undergo unnecessary surgeries.<sup>55</sup>

Doctors have the responsibility to adequately inform their patients about screening and access to quality health care for cancer. When patients are not receiving full disclosure of their options regarding health care from their doctors, then it implies that they cannot take into account the material risks and reasonably available alternatives to the proposed course of conduct. Such practices can lead to inferior care and treatment because the patients are not able to evaluate or consider healthier alternatives. Thus, the practitioners are not legitimately obtaining informed consent because they will have failed to inform their patients with the necessary material information, even though the patient has consented to a certain treatment.

## **V. Conclusion**

The lack of informed consent has had an enormous impact on the health inequality between minorities of color, particularly African-Americans, and Whites. A practitioner's bias and prejudices towards a minority result in a lack of transparency to fully disclose the patient's best options regarding health care. These practices could then translate to poorer treatment of cancer for many minorities of color.

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<sup>52</sup> Dovidio & Fiske, *supra* note 16, at 948.

<sup>53</sup> Dovidio & Fiske, *supra* note 16, at 948.

<sup>54</sup> Dovidio & Fiske, *supra* note 16, at 945.

<sup>55</sup> Dovidio & Fiske, *supra* note 16, at 945.

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The emerging trend is for patients to take a more active role in their health care by deciding which treatments are the most appropriate for their circumstances, instead of merely following the will of their doctors.<sup>56</sup> This active participation may induce the practitioner to more comfortably disclose and inform the patient of all material information. This may help to eliminate the disparity among minorities of color from being inadequately informed, which will hopefully translate into fewer cancer and death disparities among African-Americans compared to Whites. The key change will be encouraging stronger, more stable patient-doctor relationships.<sup>57</sup>

One legislative proposal is for states to enact laws that mandate practitioners to attend annual cultural competency classes, which would help doctors counteract the influence of potential bias.<sup>58</sup> These courses would involve the development of culturally competent skills, and would direct practitioners to develop effective self-regulation to diminish subtle bias.<sup>59</sup> Hospitals can also adopt policies that require doctors and nurses to attend cultural competency classes. Once physicians comprehend the full complex nature of biases and stereotyping, they will be better equipped to provide higher-quality care more equitably.<sup>60</sup>

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<sup>56</sup> Roe, *supra* note 14, at 205–06.

<sup>57</sup> CAPITMAN, BHALOTRA & RUWE, *supra* note 1, at 6; Dovidio & Fiske, *supra* note 16, at 949.

<sup>58</sup> Dovidio & Fiske, *supra* note 16, at 949.

<sup>59</sup> See Dovidio & Fiske, *supra* note 16, at 949.

<sup>60</sup> Dovidio & Fiske, *supra* note 16, at 949.

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