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## Tell Me a Story: Using Short Fiction in Teaching Law and Bioethics

Dena S. Davis

For some years now, I have been experimenting with the use of short fiction in my upper-level class on Biomedical Ethics and the Law. Biomedical ethics is a subject nourished by stories. One can almost chart the course of legal progress in bioethics by invoking the names of the leading characters: Karen Quinlan,<sup>1</sup> Nancy Cruzan,<sup>2</sup> Baby M.<sup>3</sup> It is these people and their problems, and the often conflicting wishes of the people who love and care for them, that capture students' imagination and make bioethics such a compelling field of study. The family of Nancy Cruzan, for example, generously allowed themselves to be featured in a *Frontline* program so affecting that my students always choke up when viewing it. (A particularly instructive moment for law students is when the lower court's opinion is handed to the Cruzan family at home and they are left alone to puzzle out "where the important stuff is" and who actually won.) Donald Cowart, now called Dax, a burn victim who was treated against his will, is the subject of two documentaries,<sup>4</sup> numerous essays,<sup>5</sup> and at least one book.<sup>6</sup>

It is also important to expose students to stories that do not end up in court. Students without a health care background often need reminders that most cases of treatment refusal, for example, are resolved privately between patient (if competent), family, and health care professionals. Richly detailed accounts of such cases, such as Martha Weinman Lear's description of her husband's battle with heart disease,<sup>7</sup> Betty Rollin's account of helping her terminally ill

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1. *In re Quinlan*, 355 A.2d 647 (N.J.), cert. denied, 429 U.S. 922 (1976).
2. *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261 (1990).
3. *In re Baby M*, 537 A.2d 1227 (N.J. 1988).
4. *Please Let Me Die* (Galveston, 1974); *Dax's Case* (New York, 1984).
5. E.g., Robert B. White, *A Demand to Die*, *Hastings Center Rep.*, June 1975, at 9; H. Tristram Engelhardt, Jr., *A Demand to Die*, *Hastings Center Rep.*, June 1975, at 10.
6. *Dax's Case: Essays in Medical Ethics and Human Suffering*, ed. Lonnie D. Kliever (Dallas, 1989).
7. *Heartsounds* (New York, 1980).

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mother commit suicide,<sup>8</sup> and Timothy Quill's story of respecting his patient's refusal to try one last round of chemotherapy for her leukemia, and helping her to die instead,<sup>9</sup> are invaluable resources.

Another source for stories is the experience of students, guest speakers, and perhaps the instructor. I think most teachers encourage students to speak of their experiences as health care providers but discourage stories in which students or family members are *receivers*, perhaps fearing that the class will degenerate into touchy-feely show-and-tell. But someone who volunteers to discuss her own experience can provide an important element, properly channeled.

Despite these rich resources for stories, there remains a void best filled by fiction. When discussing fiction, we can probe, criticize, and express ourselves freely without the constraints we feel when discussing real people. Good fiction lays bare the innermost thoughts and experiences of its characters, perhaps even their dreams and nightmares, in a way that would be intrusive, uncomfortable, or impossible, even in autobiography. When the entire class reads a short story, it provides a pool of shared experience, a fixed point for discussion. Just as we refer repeatedly to major cases over the course of a semester, these short stories become part of our "bodied stuff on which to feed"<sup>10</sup> and enrich class discussions in unpredictable ways.<sup>11</sup>

Here I describe how I use one short story in a week of classes devoted to the study of informed consent.

The doctrine of informed consent is the bedrock of biomedical ethics but often a shaky foundation. As Jay Katz has said, "It has been employed with little care but great passion to voice a dream of personal freedom and individual dignity."<sup>12</sup> Most students approach informed consent in a positive way: they approve of the doctrine, assume that they know what it means, and believe in the principle of respect for autonomy on which it is grounded. After all, who could argue with Judge Cardozo's ringing declaration that "every human being of adult years and sound mind has a right to determine what shall be done with his body?"<sup>13</sup> But when the class tries to pin down what this means in terms of a physician's duty to explain certain things to a patient, especially given the radical inequality of their medical knowledge, the discussion gets much more complex. *Canterbury v. Spence*,<sup>14</sup> the leading case, describes the physician's responsibility:

8. Last Wish (New York, 1985).

9. Death and Dignity: Making Choices and Taking Charge (New York, 1993).

10. Clifford Geertz, The Interpretation of Cultures: Selected Essays 23 (New York, 1973).

11. I have written elsewhere about the use of fiction to supply us with "rich cases" that do not run the risk of violating patient confidentiality. Rich Cases: The Ethics of Thick Description, Hastings Center Rep., July-Aug. 1991, at 12.

12. Legal and Ethical Issues of Consent in Health Care, in 3 Encyclopedia of Bioethics, rev. ed., 1256, 1256 (New York, 1995).

13. *Schloendorff v. Society of New York Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

14. 464 F.2d 772 (D.C. Cir. 1972).

[T]he patient's right of self-decision shapes the boundaries of the duty to reveal. That right can be effectively exercised only if the patient possesses enough information to enable an intelligent choice. The scope of the physician's communications to the patient, then, must be measured by the patient's need, and that need is the information material to the decision. Thus the test for determining whether a particular peril must be divulged is its materiality to the patient's decision: all risks potentially affecting the decision must be unmasked.<sup>15</sup>

Although the goal articulated here—empowering patients to exercise their right of self-decision in a meaningful way—is admirable, the language is rather murky when tested against actual people in real situations. “Information material to the decision” may vary quite a bit from one patient to another, depending on their values, idiosyncracies, culture, vocations and avocations, tolerance for discomfort, and so on.

To challenge a facile allegiance to a static notion of informed consent, I approach the topic by assigning the short story *So You're Going to Have a New Body!* by Lynne Sharon Schwartz,<sup>16</sup> a contemporary writer with a feminist perspective. This is a sharply edged account of a woman in her thirties, married with three children, who undergoes a hysterectomy (and is also pressured by the doctor into having her ovaries removed, “as long as I'm in there”) because she has a large fibroid growth. The relentlessly cheery, simplistic language of the pamphlets available in the doctor's office is in sharp but subtle contrast to her subjective experience:

Over the next few weeks you get acquainted with your new body. A peculiar thing—though it does not look very different, it does things differently. It responds to temperature differently and it sleeps differently. . . . It eats differently, shits differently, and pisses differently. You suspect it will fuck differently, but that you will not know for a while. . . . It doesn't menstruate, naturally. You can't truthfully say you miss menstruation, but how will you learn to keep track of time, the seasons of the month? A wall calendar? But how will you know inside? Can it be that time will feel all the same, no coming to fruition and dropping the fruit, no filling and subsiding, moist and dry, moving towards and moving away from?<sup>17</sup>

When she experiences hot flashes, of which she had not been warned, the physician briskly informs her that all will be fixed by hormones, “nature's way.” This is her first encounter with the pills:

15. *Id.* at 786.

16. *In The Melting Pot and Other Subversive Stories* 42 (New York, 1987). My practice has been to use short fiction written by contemporary authors in an “accessible” style. I am not averse to assigning stories by suspense writers (Celia Fremlin, *A Lovely Day to Die*, in *A Lovely Day to Die and Other Stories* 11 (Garden City, 1984), about a woman who cannot bring herself to fulfill her pledge to put an end to her demented mother's life) or science fiction (Ursula K. Le Guin, *Mazes*, in *Buffalo Gals and Other Animal Presences* 61 (Santa Barbara, 1987), which puts the reader in the position of an animal in a lab experiment). In undergraduate classes on death and dying, it is common to use more substantial works, most notably Tolstoy's *The Death of Ivan Ilych*. But I find it impractical to take the time to unpack a story as dense as that—for example, to explain to students Tolstoy's romanticization of the Russian peasant class. In any case, it is a little odd (and perhaps threatening) to assign fiction to law students; why not make it an enticingly easy experience?

17. Schwartz, *supra* note 16, at 51.

[The doctor] explains how to take them—three weeks on and one week off, in imitation of nature’s way. . . . At home, standing at the bathroom sink, you extricate a pill from its tight childproof . . . niche, feverishly, like a junkie pouncing on her fix. Nature’s way. Now no more “sweats,” no more tears. Your new body is complete. What is this little piece of paper in the sample packet? Not so little when you open it up, just impeccably folded. In diabolically tiny print it explains the pills’ bad side effects or “contraindications”. . . . Most of them you already know from reading books, but there is something new. The pills may have a damaging effect on your eyes. Fancy that. Nature’s way? You settle down on the edge of your bathtub and go back to the beginning to read more attentively. First, a list of situations for which the pills are prescribed. Funny, you do not find “hysterectomy.” Reading on, you do find “female castration.” That must be . . . yes indeed, that’s you. You try to read on, but the print is so terribly small, perhaps the pills are affecting your eyes already, for there is a shimmering film over the fine letters.<sup>18</sup>

In the three years that I have used this story, students have responded variously. A number of them, particularly older women, have been impatient with the character’s “overblown” reaction, urging her to “get a grip.” Many students have pointed out that the protagonist, clearly an educated woman who was not making an emergency decision, could have done a great deal more to inform herself, instead of passively relying on her doctor to tell her everything she needed to know. But even those students critical of the protagonist have agreed that the doctor was egregiously paternalistic and that he failed by almost any reckoning to fulfill the legal or ethical requirements of informed consent. Returning to the language of *Canterbury*, there were clearly many factors “material to the decision” that the doctor had not “divulged.” In fact, if there is a weakness to Schwartz’s story for my purposes, it is that the doctor is too obviously in the wrong. He hasn’t even made a good-faith effort to inform his patient.

I ask the class to talk about what the doctor could have done to ensure that his patient was informed at the level envisioned in *Canterbury*. Inevitably, we discuss whether it is ever possible for a male doctor to communicate what it feels like to have a hysterectomy. Should we then require that the information be given only by female physicians? By female nurses? Only by physicians or nurses who have had hysterectomies themselves? Even if the latter were possible, it is obvious that the subjective *and* objective experience varies widely. (The students who want the protagonist to “get a grip” often talk about a relative or a friend who has had a hysterectomy and seems to have experienced little emotional trauma.)

As the class discussion takes off, students have many creative suggestions for ways this woman could have been better informed. Whether on the doctor’s referral or on her own initiative, she could have met with other patients who had had the procedure, or with self-help and support groups. Books such as *Our Bodies, Ourselves*, from the Boston Women’s Health Collective,<sup>19</sup> present a refreshingly skeptical view of the orthodoxies of modern medicine, and might

18. *Id.* at 50.

19. *The New Our Bodies, Ourselves: A Book By and For Women* (New York, 1984).

have spurred the protagonist to question her doctor's decision and to take a less passive role from the beginning. It seems reasonable to expect that, had she truly made this decision jointly with her doctor, after weighing all the available information, she would have been in a better position to deal with the inevitable surprises engendered by her individual subjective response.

I complete our discussion of *So You're Going to Have a New Body!* by returning to *Canterbury* and its legal requirement of informed consent. The students agree that the doctor in the story failed abysmally to meet his ethical and legal responsibility, but they also realize, first, that the patient had some responsibilities to herself that she failed to meet and, second, that no amount of information, even by a doctor truly committed to the principles of patient autonomy and informed consent, could ever have totally prepared this woman for her experience. Perhaps this is the true informed consent: to understand that a priori knowledge is always imperfect.

I then point out that people can respond in various ways to this inevitable gap between the ideal—that the patient understand everything that would have a material effect on her decision—and the reality. One can use it as an excuse, throw up one's hands, and refuse to take informed consent seriously. This was a common response in the 1970s, and one that is certainly not absent today. My class encounters it in a reading by Eugene Laforet, "The Fiction of Informed Consent."<sup>20</sup> This is a scathing attack on the legal concept of informed consent, made particularly poignant by the author's singling out for his special scorn the insistence of another physician (in 1972) that women about to undergo surgery for breast cancer be informed that radical mastectomy has not been proved to be more efficacious than other options and that "we simply do not know which method is best." Because Laforet does not want to share decision-making with his patients, he draws the conclusion that the inevitable gaps in our ability to inform a patient of *everything* he or she would want to know (particularly if we adopt the point of view of what the patient *after* the procedure would wish to have known *before* the procedure) means that there is no obligation to try. He concludes: "Informed consent is a legalistic fiction that destroys good patient care and paralyzes the conscientious physician. . . . The term has no place in the lexicon of medicine. The integrity of the physician continues to represent the most effective guarantee of the rights of the patient and of the experimental subject."<sup>21</sup>

Other physicians take the difficulties of informed consent as a challenge to be overcome. I end this class unit by showing a short videotape demonstrating the brainchild of a group called the Foundation for Informed Decision Making. The foundation produces interactive video programs that provide information about specific medical conditions (e.g., high blood pressure, breast cancer) along with descriptions of the benefits and harms associated

20. *In Ethical Issues in Modern Medicine*, eds. John D. Arras & Nancy K. Rhoden, 95 (Mountain View, Cal., 1989).

21. *Id.* at 99.

with the treatment alternatives.<sup>22</sup> The program is designed to be part of a process that includes discussions between patient and physician. With the help of the medical staff, the patient enters his own relevant information (e.g., age, symptom status, medical history), enabling the program to give individually tailored responses to his questions. Patients are presented with menus from which they can select topics they wish to learn more about. For each possible treatment (or no-treatment) alternative, viewers see real patients explaining why they chose the route they did, and what benefits and harms they experienced. The viewer comes away from a session with a printed summary of the material that has been presented.

The tape I show the class concentrates on benign prostate hyperplasia (enlarged prostate). For this condition, a patient might choose surgery, which relieves immediate symptoms but carries attendant risks, including impotence, or "watchful waiting," which has its own benefits and drawbacks. Because our earlier discussion of hysterectomy was so heavily freighted with gender issues, it is interesting to turn the tables and describe a problem faced only by men.<sup>23</sup> The video patient who has chosen surgery describes the great satisfaction he feels in once again being able to "write my name in the snow." The women in the class—myself included—admit that we would never have thought of that as a factor in choosing a treatment modality!

Again, the class compares the quality of information given through this interactive video with the legal standard of informed consent and the experience of our fictional patient. We conclude that, although the *Canterbury* ideal may elude our grasp, it is certainly possible to come close, even to the extent of helping patients anticipate their subjective responses to issues that carry a great deal of emotional baggage.

Throughout our class discussion, it is extremely helpful to have the short story as part of our shared material. Although many students challenge its realism and are impatient with the protagonist's passivity and bitterness, all the students refer to the story during our discussions and use it to make points about our topic of informed consent. Most students feel that the story has helped them to push beyond the obvious definition of informed consent. Many students say that they have read it more than once. Once they get beyond the strangeness of being asked to read fiction in law school, most students find it a helpful and enjoyable experience—and they even say so in their anonymous evaluations.

22. Joseph F. Kasper et al., *Developing Shared Decision-Making Programs to Improve the Quality of Health Care*, 18 *Qual. Rev. Bull.* 183 (1992).

23. One of the many reasons I value *So You're Going to Have a New Body!* is that I think it is important to confront gender issues in biomedical ethics, and especially in informed consent. The imbalance of power that is always present in the doctor-patient relationship (because the patient is sick, perhaps afraid, and usually ignorant) is deepened when the doctor is male and the patient is female. For most of Western medical history, doctors have been overwhelmingly male and have treated women with scant respect. When the particular medical problem is one connected with gender, issue is piled upon issue. In my class I want to encourage a substantive discussion about gender issues, in a way that will force students to think hard but will avoid unnecessary discomfort. Fiction is a great help here. It would be much more difficult to discuss the sexual experiences of a real person. Fiction is both challenging and "safe."