

Face to Face with “It”: And Other Neglected Contexts of Health Privacy¹

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“ILLNESS has recently emerged from the obscurity of medical treatises and private diaries to acquire something like celebrity status,” Professor David Morris astutely observes.² Great plagues and epidemics throughout history have won notoriety as collective disasters; and the Western world has made curiosities of an occasional “Elephant Man,” “Wild Boy,” or pair of enterprising “Siamese Twins.”³

However, it is something new that fame is routinely achieved by a parade of commercial medications (like Prozac and RU-486); diseases (like bipolar disorder and autism); and ill individuals (like Philadelphia’s own Butch Quinn, who received an experimental mechanical heart transplant, and Jesse Gelsinger, who underwent gene therapy and died). Publicized illness adds a new order of celebrity to men and women who have already achieved fame. Early onset Parkinson’s added public interest to the life of television actor Michael J. Fox, much as AIDS added fascination to basketball superstar Earvin “Magic” Johnson; and schizophrenia added interest to the life of Nobel laureate John Forbes Nash.

Illness has gained celebrity, and Americans have become more open about personal health matters. Just a few decades ago, one would have been expected to share medical problems sparingly, and mainly inside the circle of intimate family and friends. It was considered uncouth by the middle and educated classes to prattle on about poor digestion,

¹Read 24 April 2004, as part of the symposium “Privacy.”

²David B. Morris, *Illness and Culture in the Post Modern Age* (Berkeley: University of California Press, 1998), 62.

³Englishman Joseph Carey Merrick, nicknamed “The Elephant Man,” suffered from a severe form of a rare, disfiguring disorder called Proteus Syndrome. Eng and Chang Bunker, the original so-called “Siamese Twins,” were conjoined twins who lived, married, and prospered in the United States until their deaths in 1874. For a scholarly account of perhaps the most famous of the European “wild boys,” see Harlan Lane, *The Wild Boy of Aveyron* (Cambridge: Harvard University Press, 1979).

arthritis, menopause, and sexual dysfunction. Yet, in a wide variety of social and professional settings, talking about personal health is perfectly acceptable today. Urbane young adults freely chat about their carpal tunnel syndrome, migraines, and antidepressants.

Today, when serious illness strikes—whether cancer, multiple sclerosis, Alzheimer’s, or AIDS—it is common to share the news with friends, neighbors, and employers; publishing an account of a medical ordeal in a magazine or newspaper or on the Internet is also commonplace. Moreover, numerous popular reality television programs follow the course of real people’s hospital care. Patients voluntarily Webcast childbirth, cosmetic procedures, and cancer surgery.

PRIVACY ISN’T EVERYTHING: THE BENEFITS OF HEALTH DISCLOSURE

The new openness about health concerns has public health and private health benefits.⁴ For example, freely sharing health information with family and friends makes it easier for them to serve as appropriate caregivers. Freely sharing health information with nurses and doctors makes it possible to receive appropriate medical care. Sharing health information with employers makes it possible to receive important disability accommodations and sick leaves. Sharing information with managed care administrators and insurance companies can be unpleasant, but useful and necessary because they pay the bills, and need to do so accurately and efficiently. The same is true of sharing health information with government administrators who process applications for, for example, Medicaid, or who administer public health services. In the case of children and students, sharing health information with schools is imperative for the design of appropriate, fair, and safe programs of instruction. Schools need to know about vaccinations, allergies, hearing and sight losses, learning disabilities, and emotional disturbances.

PRIVACY STILL MATTERS

Medical openness is beneficial, and a willingness to share medical data is a practical necessity. But medical privacy has not lost all of its value and appeal. Indeed, a preference for privacy is a familiar dimension of the experience of ill health. When we are encountering ourselves as unwell or dying, many of us seek to conceal the fact and extent of our problems from others. We get picky about who knows what, about when and how our health information is passed along.

⁴ See Anita L. Allen, *Why Privacy Isn’t Everything* (Lanham, Md.: Rowman and Littlefield, 2003).

Although as a society we have grown more open about health matters, deeply felt preferences for privacy remain. I believe these are worth protecting. Fortunately, the weight of current governmental and non-governmental policy rightly assumes the continuing social value of selective concealment and consensual disclosure of health information. Unfortunately, as health information privacy is finally getting the attention it deserves, little is being done to address health privacies that cannot be reduced to the protection of data.

But first the good news. Health insurance reform, the AIDS epidemic, the Human Genome Project, and the Internet all spawned proposals for federal legislation regulating health privacy. Every state has adopted medical record confidentiality laws, including some that are disease-specific. Federal regulations now mandate more health information privacy in clinical care and research than ever before.

Congress enacted the Health Insurance Portability and Accountability Act of 1996 (HIPAA).⁵ The statute mandated efficiency in health finance administration through electronic standardization of medical records. More familiarly, the statute mandated medical information privacy through rules requiring confidentiality and patient consent for dissemination of physician medical records to third parties. Privacy rules called for by HIPAA were promulgated by the Department of Health and Human Services. Medical records are still available to insurers, researchers, and law enforcement, but they are less available to employers, marketers, and certain others.

Now for the bad news. Most health privacy law merely regulates access to health information, information in medical records, and the confidential conversations among medical providers or providers and patients. However, the desire for medical privacy is fuller-bodied than the usual discussions of physician/patient confidentiality and access to medical data suggest. Desires for solitude, dignity, and intimacy surround the experience of illness and injury. These are neglected in our bloodless contemporary obsession with the confidentiality and electronic security of health data.

⁵ Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat 1936 (1996) (HIPAA). Concerning HIPAA: "The privacy provisions of the federal law, the Health Insurance Portability and Accountability Act of 1996 (HIPAA), apply to health information created or maintained by health care providers who engage in certain electronic transactions, health plans, and health care clearinghouses. The Department of Health and Human Services (HHS) has issued the regulation, 'Standards for Privacy of Individually Identifiable Health Information,' applicable to entities covered by HIPAA. The Office for Civil Rights (OCR) is the Departmental component responsible for implementing and enforcing the privacy regulation." Department of Health and Human Services, <http://www.hhs.gov/ocr/hipaa/bkgrnd.html> (official Web site of the United States Department of Health and Human Services, last visited 17 July 2002).

SMILE FOR THE DOCTOR, HENRY

On 23 September 1970, Henry Berthiaume was dying of cancer in a hospital room in the state of Maine. His wife was at his bedside. In walked Dr. Loring Pratt, whom Henry had not seen for about three weeks. A nurse accompanied the doctor. Dr. Pratt, a specialist in the field of otolaryngology, had been Henry's surgeon, treating his larynx cancer by performing a laryngectomy. Later, when a malignant tumor appeared in Henry's neck, Pratt performed a radical neck dissection.

Henry Berthiaume and Dr. Loring Pratt had fought a valiant fight, but to no avail. Now, the end was near for Henry. Medically speaking, there was nothing else Dr. Pratt could do for Henry. Still, Dr. Pratt paid the dying man one last visit. But why? Was it a social visit to offer sympathy and comfort? It was not. Dr. Pratt came to take pictures.

Dr. Pratt's photo shoot is memorialized in the opinion of Judge Pomeroy of the Maine high court, issued in a lawsuit against the physician.⁶ Doctors are used to being sued for medical malpractice, but this was something quite different. The administrator of Henry Berthiaume's estate brought a lawsuit on the dead man's behalf for invasion of privacy and assault and battery.

The same man who had tried to save Henry's life, made the final hours of his life more miserable ones. As described by the court,

[E]ither Dr. Pratt or the nurse, at his direction, raised the dying Mr. Berthiaume's head and placed some blue operating room toweling under his head and beside him on the bed. The appellee [Dr. Pratt] testified that this blue toweling was placed there for the purpose of obtaining a color contrast for the photographs which he proposed to take. He then proceeded to take several photographs of Mr. Berthiaume.

. . . Mr. Berthiaume protested the taking of pictures by raising a clenched fist and moving his head in an attempt to remove his head from the camera's range. [Dr. Pratt] . . . himself testified that before taking the pictures he had been told by Mrs. Berthiaume when he talked with her in the corridor before entering the room that she "didn't think that Henry wanted his picture taken."

It is the raising of the deceased's head in order to put the operating room towels under and around him that appellant claims was an assault and battery. It is the taking of the pictures of the dying Mr. Berthiaume that [the Estate] . . . claims constituted the actionable invasion of Mr. Berthiaume's right to privacy.⁷

⁶ *Estate of Henry Berthiaume v. Loring Pratt*, 365 A.2d 792 (Me. 1976).

⁷ *Id.* at 793.

A lower state court had rejected the claim against Dr. Pratt and had directed a verdict in his favor. But while recognizing the “benefit to the science of medicine which comes from the making of photographs of the treatment and of medical abnormalities found in patients” the high court held that a directed verdict was a reversible error and ordered a new trial. The court expressly recognized (for the very first time) that the right to privacy existed in the state of Maine, and held that a jury could find both that Dr. Pratt invaded Mr. Berthiaume’s right to privacy and that he committed an assault and battery.

ABOUT FACE

I believe the Maine court reached the right conclusion for two reasons. First, there is something highly private about representations of the human face. For a hundred years American courts have recognized a moral and legal interest in not having photographs of oneself taken and publicized without permission. Indeed the privacy of the face was the first privacy right recognized by a state supreme court, a hundred years ago.⁸ Faces are special: “The facial characteristics or peculiar caste of one’s features, whether normal or distorted, belong to the individual and may not be reproduced without his permission. Even the photographer who is authorized to take a portrait is not justified in making or retaining additional copies for himself.”⁹

There is something especially private, too, about the post-surgical body. After a surgery, especially major craniofacial surgery and ampu-

⁸ See *Pavesich v. New England Life Insurance Co.*, 122 Ga. 190; 50 S.E. 68; 1905: “Liberty includes the right to live as one will, so long as that will does not interfere with the rights of another or of the public. One may desire to live a life of seclusion; another may desire to live a life of publicity; still another may wish to live a life of privacy as to certain matters and of publicity as to others. One may wish to live a life of toil where his work is of a nature that keeps him constantly before the public gaze; while another may wish to live a life of research and contemplation, only moving before the public at such times and under such circumstances as may be necessary to his actual existence. Each is entitled to a liberty of choice as to his manner of life, and neither an individual nor the public has a right to arbitrarily take away from him his liberty.”

⁹ Quoting *Clayman v. Bernstein*, 38 Pa. D. & C. 543 (1940), in which a plaintiff who experienced mental anguish sued a physician to enjoin his developing film and printing photos from negatives of photographs of her disfigured face following medical treatment: “A man may object to any invasion, as well as to an unlimited invasion. . . . Plaintiff’s picture was taken without her authority or consent. Her right to decide whether her facial characteristics should be recorded for another’s benefit or by reason of another’s capriciousness has been violated. The scope of the authorization defines the extent of the acts necessary to constitute a violation. If plaintiff had consented to have her photograph taken only for defendant’s private files certainly he would have no right to exhibit it to others without her permission. Can it be said that his rights are equally extensive when even that limited consent has not been given?” *Id.* at 546–47.

tations, patients are left with concerns about body image and social acceptance that may lead to new, stronger privacy preferences, rooted in vulnerability, fear of rejection or discrimination, and shame. Hiding what one regards as disfigurements beneath a bed sheet, clothing, or bandage is a way to reduce social anxieties, bolster self-esteem, and avoid unwanted attention.

THE SANCTITY OF DYING

The second reason I agree with the holding of this case, is that the dying have special, complex needs for privacy, intimacy, and flexible choices. Sometimes the dying want to be alone. Sometimes they do not want to be alone, but want to be only with particular people who know them well. These privacy preferences can be utterly unreasonable in situations that require sharing, accountability, or collective efforts. Yet there are occasions when nothing less than respect for human dignity and welfare demand that the unwanted stranger, and even the unwanted friend, stay away. Illnesses, including the hopeless ones that spell the end of life, are such occasions. At such a time, if the dying person is cognizant of the world around him or her, his or her need for privacy and selective intimacy is great. Dying is a time of acceptance, reconciliation, religious ritual, and final intimate exchanges with close friends and family. Dr. Pratt did not seem to grasp these things.

HE DOESN'T LISTEN, DOCTOR

Leo Tolstoy's novella *The Death of Ivan Ilyich* tells the story of the dead and dying Ivan Ilyich. Ivan was a once proud and prospering public servant doomed to leave this world at the age of forty-five. Ivan had an ambivalent relationship with privacy. All of us, when we are dying, want to be alone, and then again we do not want to be alone.

Tolstoy writes of Ivan that "[l]et alone, he feels horribly depressed, wants to call someone, but knows before hand that with others present it will be even worse." Solitude is difficult in the context of terminal illness because in solitude we more easily come face to face with "It," the singular reality of our own mortality. That reality can be terrifying, especially to someone suddenly faced with premature death. Quoting Tolstoy, describing Ivan:

He went to his study, lay down, and once again was left alone with It. Face to face with It, unable to do anything with It. Simply look at It and grow numb with horror.

When visited by his friend Pyotr, Ivan found an excuse to keep the man with him longer than he was really needed:

Pyotr headed for the door. Ivan Ilyich was terrified at the thought of being left alone. “What can I do to keep him here,” he thought, “Oh, of course, the medicine.”

“Pyotr, give me my medicine.”

As we die, we want to be visited, cared for, comforted, and so, we want not to be alone.

And yet, like Ivan, we can at times feel too self-conscious for company. In company we can feel pathetic, and repulsive. Ivan was “horrified, particularly horrified to see the limp way his hair clung to his pale brow” and “knew he would be even more horrified by the sight of his body so while his shirt was being changed he avoided looking at it.”

In the company of others while ill one can feel patronized and guilty. This especially bothered Ivan Ilyich: “[O]thers will lie to make you feel better, blame you for your illness.” Ivan’s self-absorbed wife was masterly at the guilt trip: “He just doesn’t listen you know,” she told Ivan’s doctor.

JUST FOOTAGE

It was a terrible automobile accident. Two members of the Shulman family were trapped inside a car that had gone off the road. A rescue helicopter was dispatched to the scene to quickly transport the victims to a hospital. The Shulmans survived and recovered from their nightmare. But then something made them heartsick. They watched their ordeal on a documentary television show, *On Scene: Emergency Response*.¹⁰ No permission had been sought or given. The Shulmans claimed in a lawsuit that the television producers had “intruded into a realm of personal privacy and gave unwanted publicity to private events of their lives.”

When the “medical transport and rescue helicopter crew came to plaintiffs’ assistance,” they were “accompanied . . . by a video camera operator employed by a television producer.” Unknown to the accident victims at the time of the wreck, “The cameraman filmed plaintiffs’ extrication from the car, the flight nurse and medic’s efforts to give them medical care during the extrication, and their transport to the hospital in the helicopter. The flight nurse wore a small microphone that picked up her conversations with other rescue workers and with one of the plaintiffs.”

We are human beings with dignity and personality. We are more than news footage. We feel that our moments of agony, our confrontations with “It” should be respected with privacy. In addition, the visceral sources of shame and embarrassment attendant to illness and injury are

¹⁰ *Ruth Shulman et al., Plaintiffs and Appellants, v. Group W Productions, Inc., et al.*, 18 Cal. 4th 200; 955 P.2d 469; 74 Cal. Rptr. 2d 843 (1998).

unpleasant to acknowledge privately, much less speak and write about. Sick people seldom resemble the ideal products of diet, exercise, cosmetic surgery, airbrushing, and electronic enhancement dished out by the media. The sight, sound, and smell of unhealthy bodies can be unpleasant. Sadly, we may be repulsed by our unwell or declining bodies and correctly believe that others are, too. Pain, one of the key indicia of unwellness, can itself be a source of embarrassment. Pain can trigger emotions and behaviors we are embarrassed to let others observe. Pain, like other symptoms of illness, can turn sufferers into objects of unwanted pity and attention. Self-esteem premised on beauty, vigor, or independence sometimes goes out the window with illness and aging, to be replaced with feelings of low self-esteem and heightened vulnerability.

WHY PRIVACY?

As standard accounts of the value of health privacy emphasize, people rely upon privacy to help control or limit health disclosures that could result in tangible, material losses.¹¹ Potential losses can be major. They include loss of employment, loss of insurance, loss of school choice, loss of community standing, and loss of intimacy.¹² Protecting health information through privacy policies serves an important material loss minimization function in a world in which discrimination and rejection can flow from news of health or genetic status.

Even when people do not have to worry much about whether health disclosure will result in the sorts of material losses just named, they will often seek privacy nonetheless. Mr. Berthiaume was not concerned about losing his job or social standing, nor was Ruth Shulman. People commonly rely upon seclusion and intimacy, as Ivan Ilyich did with considerable ambivalence at first, to facilitate what I term "responsive reflection." Self-consciously or instinctively, when a person first discovers a health problem, she may want to be alone and secretive in order to allow herself time to react, reflect, and make plans. Some health problems require a good deal of planning about how to meet responsibilities

¹¹ Lawrence O. Gostin and James G. Hodge Jr., "Piercing the Veil of Secrecy in HIV/AIDS and Other Sexually Transmitted Diseases: Theories of Privacy and Disclosure in Partner Notification," *Duke Journal of Gender Law and Policy* 5 (1998): 9–88, 66, 70; and Lawrence Gostin, Joan Turek-Brezina, Madison Powers, and Rene Kozloff, "Privacy and the Security of Health Information in the Emerging Health Care System," *Health Matrix: Journal of Medicine* 5 (1995): 1–36, 2, 21–24, stressing autonomy values and justice concerns. See generally, Charles Culver, James Moor, William Duerfeldt, Marshall Kapp, and Mark Sullivan, "Privacy," *Professional Ethics* 3.3 and 4 (1994): 3–25.

¹² See, e.g., Neil Holtzman and David Shapiro, "The New Genetics: Genetic Testing and Public Policy," *British Medical Journal* 316 (7134): 852–56 (1998), who describe denial of health and life insurance, along with employment constraints, as risks of genetics-related health disclosures.

and answer accountability imperatives. Privacy functions as a tool for responsive reflection, that is, reflection in response to new information and belief about personal health.

Privacy allows for what might be termed “emotional distress minimization.” The discovery of health problems may cause anxiety and emotion. Unfortunately, for some, illness leads to shame, embarrassment, and defeat that lower self-esteem and increase feelings of vulnerability. Imagine how Henry Berthiaume must have felt with a gaping hole in his neck. Hoping to manage common forms of psychological distress brought on by health concerns, a person may choose solitude or seclusion. These privacies can help avoid the amplification of feelings of low self-esteem and heightened vulnerability. In this respect, privacy functions as a tool of emotional distress minimization.

Ethicists have made the moral case for material loss minimization by reference to the overlapping moral ideals of respect for dignity, autonomy, and justice. The case for responsive reflection and emotional distress minimization can be made by reference to those same ideals, but is also supported, more directly, by ideals of respect for social boundaries and needs (including intimacy, friendship, civility, trust, or accountability) and respect for psychological boundaries and needs (including solitude, repose, composure, self-expression, or reduction of social anxiety).

CONCLUSION

The seeming trend toward openness about health matters could mean most Americans are prepared to accept health information policies that stress the societal benefits of information accessibility over the societal and individual benefits of stringent privacy protection. Yet people with consistently traditional privacy sensibilities deserve protection no less than people with the newer sensibilities or idiosyncratic admixtures of old and new.

There is scant basis for believing that most Americans are prepared to surrender health privacy choices outright. It is one thing to chat with a stranger about your broken leg while waiting for coffee at Starbucks, and something else to share with anyone, under compulsion, the agonies of being face to face with “It.”

In our liberal society we need the legal policies we have got; policies that presumptively vest certain alienable rights to control health data disclosures in the individual. But we also need humane medical practices, medical research, and journalism, not addressed in our state and federal health information privacy statutes. We must think about health privacy broadly and make careful choices for ourselves, our families, and communities that show appreciation for the diversity of health privacies.